

## ANALYSIS OF THE MOTHER'S ROLE IN THE SEXUAL DEVELOPMENT OF ADOLESCENT GIRL WITH INTELLECTUAL DISABILITIES AT UPT SLB-E NEGERI PEMBINA PROVINCIAL LEVEL OF NORTH SUMATRA IN 2025

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### ABSTRACT

**Background:** Adolescents with intellectual disabilities face significant challenges in understanding sexual and reproductive health (SRH) due to cognitive limitations, stigma, and lack of appropriate education. Parents, particularly mothers, play a central role in supporting their daughters' self-care and protection during puberty. **Objective:** This study aimed to explore the lived experiences of mothers in providing sexual and reproductive health education to adolescent girls with intellectual disabilities. **Methods:** A qualitative phenomenological approach was used, involving in-depth semi-structured interviews with five mothers selected through purposive sampling. Data were analyzed using Colaizzi's method, followed by member checking, triangulation, and audit trails to ensure credibility. Ethical approval was obtained from the Health Research Ethics Committee of Universitas Sumatera Utara. **Results:** Five main themes emerged: (1) mothers' emotional journey, (2) understanding of sexual and reproductive health, (3) communication and parenting strategies, (4) social and cultural barriers, and (5) support and coping mechanisms. Mothers experienced mixed emotions—fear, shame, love, and responsibility—while navigating social stigma and limited knowledge. **Conclusion:** Mothers' experiences reflect the complexity of raising daughters with intellectual disabilities within cultural and religious contexts. The findings highlight the importance of inclusive, family-centered SRHR education and psychological support to empower parents in guiding and protecting their children.

**Keywords:** Intellectual Disability, Phenomenology, Sexual And Reproductive Health, Parenting, Adolescent Girls.

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### Introduction

Sexual development constitutes a crucial component of the individual growth process, extending to adolescent girls with intellectual disabilities. Intellectual disability (formerly mental retardation) is defined by significant limitations in intellectual functioning and adaptive skills, impacting various facets of daily life, including the comprehension and management of sexual behavior. Despite these cognitive constraints,

adolescents with intellectual disabilities undergo the same biological development as their typical peers concerning physical, emotional, and social changes (Farakhiyah, Raharjo, & Apsari, 2018).

Puberty is a pivotal stage for adolescent girls, characterized by menarche, changes in body shape, and the emergence of interest in the opposite sex. For adolescents with intellectual disabilities, this phase can precipitate confusion, anxiety, and heightened

vulnerability to sexual violence and abuse, especially in the absence of adequate sexuality education. Consequently, parental guidance, particularly from mothers, assumes a central role in assisting children to recognize their bodies, maintain reproductive hygiene, understand social interaction boundaries, and cultivate self-confidence in their identity (American Association on Intellectual and Developmental Disabilities, 2021).

In the family setting, mothers frequently play the key role in delivering sexuality education and emotional support. This maternal role aligns closely with the achievement of Sustainable Development Goal (SDG) 3, which aims to ensure healthy lives and promote well-being for all at all ages. Comprehensive sexuality education provided by mothers not only helps children understand bodily changes and appropriate conduct but also significantly contributes to protecting them from sexual violence and exploitation (UNFPA, 2022).

Various studies indicate that parents possessing a sound understanding of reproductive health are generally more proactive in providing sexuality education to their children, including those with special needs (Wahyuni, 2018). However, in practice, many mothers continue to face barriers in communicating this

information due to limited knowledge, embarrassment, cultural factors, and fears that discussing sexuality might encourage deviant behavior (Dalimunthe, 2019). Additional common obstacles involve emotional pressure stemming from parenting stress, time limitations, and the social burden associated with community stigma toward children with disabilities.

This situation underscores the gap between the genuine need of adolescent girls with intellectual disabilities for comprehensive sexuality education and the readiness of their mothers to offer appropriate guidance. Support from the broader environment, such as husbands, extended family, and schools, substantially influences the effectiveness of the mother's role. This cross-environmental interaction is best explained through Bronfenbrenner's Ecological Model, which places the individual at the center of micro (family, school), meso (interactions between systems), exo (social and cultural policies), and macro (community values and norms) systems. This model is pertinent for grasping how the maternal role is shaped and impacted by surrounding social support.

Furthermore, attachment theory (Bowlby, 1969) posits that a secure emotional bond between mother and child forms the foundation for the child's sense

of trust and preparedness to navigate pubertal changes. Concurrently, social control theory (Hirschi, 1969) highlights the importance of family supervision and attachment in preventing risky behavior among adolescents. Therefore, integrating these three theories provides a robust conceptual framework for understanding how mothers fulfill their parenting functions in the context of the sexual development of children with intellectual disabilities.

Based on a preliminary survey of three mothers who have daughters with intellectual disabilities at the Provincial Special Needs School (UPT SLB-E Negeri Pembina) in North Sumatra, findings indicated that most mothers had attempted to provide basic education regarding menstruation and reproductive organ hygiene, yet this communication was often one-way and unsustainable. Education on protection from sexual violence was also not administered systematically. This suggests that the maternal role in supporting their children's sexual development remains suboptimal and necessitates strengthening in terms of knowledge, social support, and adaptive parenting strategies.

Drawing on this background, this study adopts a phenomenological approach to explore in-depth the lived experiences of mothers in accompanying the sexual

development of adolescent girls with intellectual disabilities. This approach is chosen specifically for its capacity to focus on comprehending the subjective meaning of the participants' real-life experiences, rather than merely describing their behavior. Consequently, the results of this study are expected to yield a more comprehensive understanding of the meaning of the mother's role, the supporting and inhibiting factors, and the strategies employed in managing the dynamics of sexual development in children with intellectual disabilities.

## **Method**

This study uses a qualitative approach with a descriptive phenomenological design. The phenomenological approach was chosen to understand the meaning of the subjective experiences of mothers in accompanying the sexual development of adolescent girls with intellectual disabilities. Phenomenology focuses on the "essence of lived experience" as directly experienced by participants (Altundağ, 2024)

Phenomenological analysis in this study uses Colaizzi's (1978) method, which includes seven systematic steps, namely:

1. Reading all interview transcripts to gain a general understanding of the participants' experiences.

2. Identifying significant statements related to the phenomenon being studied.
3. Compiling the meanings of each significant statement.
4. Grouping the meanings into categories and themes that reflect the core of the mothers' experiences.
5. Compiling a comprehensive description of the phenomenon experienced by the informants.
6. Formulating the essential structure (essence of experience) from the results of the theme analysis.
7. Conducting member checking with participants to ensure the accuracy of the interpretation of the results with their actual experiences.

In the research process, researchers applied bracketing (*epoché*), which is temporarily suspending personal assumptions, values, and experiences so that they do not influence data interpretation. In addition, researcher reflexivity was carried out, which is reflective recording during the interview and data analysis process to identify potential subjective bias.

### **Research Location and Time**

The research was conducted at the North Sumatra Provincial Special Needs School (UPT SLB-E Negeri Pembina Tingkat Provinsi Sumatera Utara), located on Jl. Karya Ujung, Helvetia Timur, Medan

Helvetia District, Medan City. The location was chosen purposively because this school is a special education institution that accommodates a significant number of adolescents with intellectual disabilities and has an active communication network between teachers and parents.

The research was conducted from December 2024 to July 2025, covering the stages of preparation, data collection, analysis, and validation of results.

### **Research Subjects and Informants**

The main informants in this study were five mothers of adolescent girls with mild intellectual disabilities who attended the Pembina State Special Needs School (UPT SLB-E Negeri Pembina). Informants were selected using purposive sampling based on the following inclusion and exclusion criteria:

- Inclusion criteria:
  1. Mothers who have daughters diagnosed with mild to moderate intellectual disabilities (as evidenced by school records).
  2. Children aged 12–18 years who have reached puberty.
  3. Mothers who live with their children and are directly involved in their care.
  4. Willing to become informants voluntarily by signing an informed consent form.
- Exclusion criteria:

1. Mothers who do not live with their children on a regular basis.
2. Mothers who have communication disorders or severe cognitive impairments that hinder the interview.

In addition to the primary informant, there are supporting informants consisting of the husband, close family members (such as grandmothers or aunts), and classroom teachers. Supporting informants are selected to triangulate sources, in order to strengthen the credibility of the data and clarify the social context of the mother's role.

The number of informants was determined based on the principle of data saturation, which is when additional interviews no longer produce new themes or information (Guest, G., Namey, E., & Chen, 2020).

### **Data Collection Techniques**

Data was collected through in-depth interviews using semi-structured guidelines. The interview guidelines contained open-ended questions covering:

1. Mothers' experiences in accompanying their children's physical, emotional, and social changes during puberty.
2. The form of sex education provided to children.
3. Mothers' strategies in overcoming social barriers or stigma.

4. Support received from husbands, families, and schools.

Interviews were conducted face-to-face in school counseling rooms or informants' homes, as agreed, lasting 45–60 minutes. Each interview was recorded with the informant's permission and accompanied by field notes to record nonverbal expressions and the context of interactions.

The researcher also conducted light participatory observation in the school environment to understand the child's social interactions with their mother and teacher as supporting data.

### **Data Analysis Techniques**

The analysis was conducted simultaneously with the data collection process using Colaizzi's (1978) steps as described above. This process involved the following activities:

1. Verbatim transcription of interview results.
2. Marking of meaningful quotes (I1–I5 for main informants; G1–G2 for teachers; S1–S2 for husbands).
3. Initial coding, categorization, and identification of themes and subthemes.
4. Compilation of narrative descriptions of mothers' experiences based on key themes, such as sex education, emotional support, child independence, and behavioral supervision. The final

results are presented in a Theme–Subtheme–Representative Quote table to maintain transparency of interpretation.

### **Data Validity (Trustworthiness)**

To ensure the validity and reliability of qualitative data, this study used four criteria proposed by Lincoln and Guba (1985), namely:

1. Credibility: achieved through triangulation of sources (mother, husband, teacher), member checking, and peer debriefing.
2. Transferability: presentation of in-depth contextual descriptions so that readers can assess the applicability of the results in other contexts.
3. Dependability: researchers keep audit trail records including interview transcripts, reflection notes, and analysis processes.
4. Confirmability: maintaining objectivity by conducting self-reflection, documenting analysis decisions, and cross-checking with research supervisors.

### **Research Ethics Considerations**

This research has obtained ethical approval from the Health Research Ethics Committee of the Faculty of Public Health, University of North Sumatra, with letter number No. 78/KEPK/FKM-USU/I/2025. All participants were provided with a

research information sheet and informed consent explaining the purpose, benefits, and right to refuse at any time without consequences. Confidentiality was maintained by using initials (I1–I5) in all data and publications. Given that the research topic was sensitive, the researchers ensured safeguarding mechanisms for participants and children, including:

1. Conducting interviews in a safe, private room.
2. Do not record or quote information that could identify individuals.
3. Provide referrals to school counseling services or child protection agencies if there are indications of violence or abuse.

### **Data Management and Storage**

All digital data (audio recordings, transcripts, and field notes) are stored in encrypted form with access restricted to the principal investigator. Data will be stored for five years after publication in accordance with the ethical guidelines of the University of North Sumatra, after which it will be permanently destroyed.

## **Results**

### **General Description of Informants**

This study involved five main informants who were mothers of adolescent girls with mild to moderate intellectual disabilities, aged between 12 and 18 years, and attending the Provincial Special Needs School (UPT SLB-E Negeri Pembina

Tingkat Provinsi Sumatera Utara). In addition, there were three supporting informants, namely two teachers and one husband. All informants live with their children and play a direct role in their upbringing and education. Most of the mothers are aged 35–50 years old with a high school education background and work as housewives. All informants have known about their children's condition since early on through school diagnosis and have accompanied their children during puberty.

### **Theme 1: Mothers' Understanding of Their Children's Sexual Development**

Sub-theme 1.1: Awareness of children's physical and emotional changes

Most mothers are aware that their children are experiencing physical changes such as menstruation, breast enlargement, and emotional behavioral changes, but do not always understand that these changes are a normal part of puberty.

*“My child has had her period twice, but she is confused about why she is bleeding. I explained it to her slowly, that it is a sign that she is growing up.” (I1)*

*Some mothers view their children's emotional changes—such as being easily angered, jealous, or wanting attention—as signs of puberty, but have not yet linked them to the need for sex education.*

*“Sometimes she gets jealous when I am close to her younger sibling. I think it's because she wants more attention.” (I3)*

Sub-theme 1.2: Limited understanding of sexuality education

Most mothers consider sexuality education to be only related to menstrual hygiene, not touching on aspects of self-protection and social relations.

*“All I teach is how to use sanitary pads and bathe properly during menstruation. When it comes to boys, I rarely discuss it because I'm afraid he will misunderstand.” (I2)*

### **Theme 2: The Role of Mothers in Providing Education and Supervision**

Sub-theme 2.1: Simple education based on everyday experiences

Mothers use simple methods such as storytelling, giving examples, and reminding children whenever a relevant situation arises.

*“If I see people hugging on TV, I tell them that's not allowed. Girls must protect themselves.” (I4)*

*“I tell them that if someone wants to touch them, they must say no and quickly go to their mother.” (I5)*

*This approach shows a form of spontaneous parental teaching rooted in everyday life experiences.*

Sub-theme 2.2: Supervision of children's social interactions

Most mothers restrict their children's activities outside the home and try to

always accompany them when they are in crowded environments.

*"If they go to a shop, I tell them to take someone with them. I'm afraid there are bad people out there, because my children are innocent." (I3)*

*However, the teacher (G1) added that overly strict restrictions sometimes hinder children's socialization at school.*

*"Mothers are too protective, when in fact their children need to learn to interact with their peers." (G1)*

### **Theme 3: Barriers and Challenges in Support**

Subtheme 3.1: Limited Knowledge and Awkwardness

Almost all mothers admitted to not having sufficient knowledge about appropriate sex education for children with intellectual disabilities.

*"I'm also confused about how to explain it, afraid of making a mistake. I just tell them not to get close to boys." (I2)*

*Furthermore, cultural factors and taboos still strongly influence mothers' attitudes toward discussing sexuality.*

*"In the past, we were never taught that. So it feels strange to talk to children." (I4)*

Subtheme 3.2: Emotional Pressure and the Burden of Parenting

Some mothers feel emotionally exhausted from having to constantly monitor their children's behavior, especially during

menstruation or when they begin to become interested in the opposite sex.

*"It's tiring, having to constantly supervise them. Sometimes I'm afraid they might sneak out." (I1)*

*These feelings of anxiety and worry are often not accompanied by adequate emotional support from their partners.*

*"My husband rarely wants to interfere, he says I should leave women's affairs to him." (I5)*

### **Theme 4: Social Support and the Meaning of Mothers' Experiences**

Subtheme 4.1: Support from Family and School

Mothers who receive support from teachers or other family members feel more helped in understanding their children's behavior.

*"Teachers often tell me that my child seems confused during menstruation, so I can teach her again at home." (I3)*

*Schools also play an important role in providing additional information and a safe environment for children.*

*"At school, we also help explain about the body and boundaries, using pictures so they understand." (G2)*

Subtheme 4.2: Self-Acceptance and the Meaning of Motherhood

Through the mentoring process, mothers feel they have learned to be more patient and accepting of their children's condition.

*"I used to be ashamed of having a child like this. Now I'm grateful, because she teaches me patience and strength." (I4)*

The phenomenological essence that emerges from this theme is the "transformation of the maternal role"—the experience of mentoring a child with intellectual disabilities becomes an inner journey that teaches patience, empathy, and a sense of moral responsibility to protect children from social risks.

### **The Essential Structure of Mothers' Experiences**

The analysis reveals that mothers' experiences in supporting the sexual development of adolescent girls with intellectual disabilities reflect a complex journey involving limited understanding, adaptive strategies, emotional challenges, and diverse social support.

The essence of the phenomenon that emerged was:

*"Being a mother of an adolescent with intellectual disabilities means navigating between fear and compassion—trying to understand the child's changes, protecting them from harm, while learning to accept oneself and one's role as the primary supporter in the child's sexual development."*

### **Discussion**

This study aims to explore the meaning of mothers' experiences in supporting the sexual development of adolescent girls with

intellectual disabilities at the UPT SLB-E Negeri Pembina at the North Sumatra Provincial Level. Through descriptive phenomenological analysis, four main themes were identified: mothers' understanding of their children's sexual development, their role in education and supervision, barriers to support, and social support and the meaning of maternal experiences. These four themes describe a complex experience, encompassing interconnected emotional, social, and cognitive aspects.

#### **1. Mothers' Understanding of Children's Sexual Development**

Research results show that most mothers' understanding of children's sexual development is limited to physical and emotional changes, such as menstruation and mood swings. This knowledge does not encompass aspects of self-protection, social relationships, and reproductive health rights. This aligns with the findings of (Poerwanti, S. D., Makmun, S., Paramitha, N. A., & Kusumaningrum, 2020), who stated that parents of children with intellectual disabilities often view sexual education as taboo and focus solely on biological aspects.

Mothers' limited understanding can be explained through Bronfenbrenner's ecological theory, particularly at the microsystem and mesosystem levels.

Family factors and interactions with schools significantly influence mothers' knowledge of children's sexual issues. Lack of communication between parents and educational institutions results in inadequate communication of information about sexual education (Bronfenbrenner, 1979).

Furthermore, social and cultural norms in the surrounding environment also shape mothers' perspectives on children's sexuality. In Indonesia's conservative society, discussions about sex are often considered taboo, especially when it concerns girls. As a result, mothers experience ambivalence between the desire to protect their children and the fear of being considered impolite if they discuss this matter openly (Dalimunthe, 2019).

## 2. The Mother's Role in Education and Supervision

The mother's role in this study was divided into two main forms: simple education and supervision of children's social behavior. Mothers provided sexual education through spontaneous conversations and examples of everyday behavior, such as advising children to maintain menstrual hygiene or refusing to be touched by others. This form of education illustrates a contextual communication strategy that adapts to the child's cognitive abilities,

as suggested by (Farakhiyah, F., Raharjo, S. T., & Apsari, 2018).

From the perspective of Attachment Theory (Bowlby, 1996), a secure emotional relationship between mother and child is the foundation for successful sexual communication. When children feel unconditionally accepted and loved, they are more open to their mother's guidance. However, this study also revealed the presence of overprotective parenting styles that reduce children's opportunities for socialization. Teachers observed that some mothers tended to restrict their children's interactions due to concerns about abuse or inappropriate behavior.

Although mothers' motivation stems from love and responsibility, excessive protectiveness can actually hinder a child's social development. According to social control theory (Hirschi, 1969), family ties are crucial for preventing risky behaviors, but they must be balanced with trust and independence so that children can develop healthy self-control.

In the context of reproductive health rights (SRHR), the role of mothers as primary educators is crucial in ensuring children's right to accurate information about their bodies, menstrual hygiene, and the boundaries of social interactions. The (World Health

Organization, 2021) emphasizes that every individual, including persons with disabilities, has the right to access information and sexual education appropriate to their abilities.

### 3. Barriers and Challenges in Support

The main barriers mothers face are limited knowledge, awkwardness, and emotional stress. Some mothers admit to not knowing how to explain sexuality appropriately, while others feel embarrassed due to cultural and religious influences. Research by Wahyuni (2018) shows a similar trend, where mothers of children with disabilities tend to avoid discussing sexuality for fear of arousing their children's curiosity.

This limited knowledge is not only caused by a lack of information sources, but also by a lack of training or counseling provided to parents. Mothers feel they lack support from schools or health professionals. However, community-based information and training support has been shown to improve mothers' ability to provide safe and developmentally appropriate sexuality education for children (UNICEF, 2022).

Emotionally, some mothers experience parenting stress due to having to constantly supervise their children. This condition is exacerbated

by a lack of support from partners or family. According to Puspita et al. (2021), parenting stress in mothers of children with disabilities can reduce parenting sensitivity and impact communication patterns with their children. Therefore, interventions that focus on the mother's emotional well-being are important to maintain the effectiveness of support.

### 4. Social Support and the Meaning of Mothers' Experiences

Support from teachers, partners, and family is a crucial factor in strengthening the role of mothers. Teachers contribute by providing additional education at school and helping children visually understand physical changes. These findings reinforce Bronfenbrenner's ecological theory, where the interaction between the microsystem (family) and mesosystem (school) plays a significant role in shaping children's behavior (Bronfenbrenner, 1979).

In addition to external support, internal meanings emerged, such as self-acceptance and emotional transformation. Mothers expressed that the process of accompanying their children taught them patience, sincerity, and a deeper understanding of the value of life. This aligns with (Poerwanti, E., Wulandari, R., & Pramono, 2023)

findings that the experience of caring for children with disabilities can foster empathy and positive spirituality in parents.

From a phenomenological perspective, this meaning is the essence of the maternal experience—where suffering, love, and responsibility combine to form a source of inner strength. Accompanying children is no longer seen as a burden, but rather as a form of worship and moral devotion that enriches the meaning of a mother's life.

### **Research Limitations**

This study has several limitations, including the relatively small number of informants ( $n=5$ ) and the fact that it was conducted at a single school, making the results unable to be generalized to all social contexts. Furthermore, the sensitivity of the topic led some mothers to be cautious in their responses, which may have affected the depth of the data. Nevertheless, data validity was maintained through source triangulation, member checking, and an audit trail in accordance with COREQ standards.

### **Conclusions**

This study aims to explore the meaning of mothers' experiences in supporting the sexual development of adolescent girls with intellectual disabilities at the UPT SLB-E Negeri

Pembina at the North Sumatra Provincial Level. Using a descriptive phenomenological approach using the Colaizzi analysis method, four main themes emerged that deeply illustrate the dynamics of maternal experiences.

First, mothers' understanding of their children's sexual development is still limited to biological aspects, such as menstruation and physical changes, while psychosocial aspects and self-protection are not fully understood. This indicates a persistent gap in sexual literacy among parents of children with intellectual disabilities.

Second, mothers' role in education and supervision is evident through simple efforts, such as direct guidance, close supervision, and spontaneous communication based on everyday experiences. Despite limited educational resources, mothers serve as primary figures, providing a sense of security and moral protection for their children.

Third, the obstacles and challenges faced by mothers include limited knowledge, shame due to cultural norms, and emotional stress in raising children with special needs. These factors are often exacerbated by minimal support from partners and educational institutions.

Fourth, social support and the meaning of maternal experiences are crucial aspects that strengthen mothers'

emotional resilience. Support from teachers, family, and the community helps mothers understand their children's conditions more positively, while the parenting process fosters spiritual meaning in the form of patience, sincerity, and gratitude for the trust given.

Phenomenologically, the mother's experience can be summarized as an inner journey between fear and compassion, where the mother struggles to understand the child's changes, protect them from social risks, and simultaneously find new meaning in her mothering role. Maternal support is not only a form of physical care, but also an expression of affection rooted in moral and spiritual values.

The results of this study also confirm that a phenomenological approach can uncover the profound essence of mothers' experiences in the context of disability, which are influenced not only by individual factors but also by environmental interactions, as explained through Bronfenbrenner's Ecological Model, Attachment Theory, and Social Control Theory.

### Recommendations

Future research is recommended to explore sexuality education for children with intellectual disabilities more comprehensively by involving a wider range of participants, including fathers, teachers, children, and community or

religious leaders. Further studies should examine how family dynamics, school support systems, cultural values, and religious perspectives interact in shaping sexual literacy and protective behaviors among children with disabilities. In addition, future researchers are encouraged to develop and evaluate community-based and culturally sensitive intervention models that integrate parental guidance, school collaboration, and health service support to improve access to accurate sexual and reproductive health information. Such research is expected to contribute to the development of inclusive, effective, and sustainable strategies that support the dignity, safety, and healthy development of children with intellectual disabilities.

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