

## Identifying Contents for Teaching Sexuality Education to Children and Adolescents with Autism and Intellectual Disabilities in Nepal<sup>1</sup>

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### Abstract

This article details the process of identifying the Comprehensive Sexuality Education (CSE) contents for children and adolescents with Autism Spectrum Disorder (ASD) and Intellectual Disabilities (ID) while developing a resource booklet for teaching them CSE-related matters in the Nepalese context. People with disabilities are prone to misconceptions and stigma. Likewise, children and adolescents with ASD and ID face an increased risk of exploitation and abuse. Hence, they all deserve equal access to high-quality sexuality education. Nepal's policy supports inclusive education for learners with disabilities, but its implementation is interrupted due to many issues and obstacles. Therefore, this study aimed to create a CSE resource booklet for Nepalese children and adolescents with ASD and ID, analyzing global sexuality education teaching situations and comprehending the expectations of parents and teachers. The research involved searching documents, conducting focus group discussions with nine teachers and parents of adolescents with ID and eight teachers and parents of adolescents with ASD, and interviewing two teachers and two parents of both categories. The literature reviewed primarily focused on providing body information, appropriate sexual behaviors, relationships, safety, and hygiene. Focus group discussions and interviews revealed that guidance on sexual behavior, self-care, relationship identification, preventing sexual abuse, and menstrual hygiene management are also essential for Nepalese children and

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adolescents with ASD and ID. The teachers' resource booklet for teaching sexuality education to children and adolescents with ASD and ID was proposed to include seven main topics and 19 sub-topics, specifically focusing on the Nepalese context for the first time in Nepal.

**Keywords:** Autism spectrum disorder, comprehensive sexuality education, intellectual disability, Nepal, resource booklet, SRHR

### **Introduction**

Following the 1994 International Conference on Population and Development (ICPD), many nations have implemented Sexual and Reproductive Health and Rights (SRHR)-related legislation and regulations (Kabiru, 2019). Nepal has also ratified the ICPD Plan of Action (PoA) (1994), the Beijing Plan of Action (1995), and the Millennium Development Goal (MDG) (2000) as well as the Convention on the Elimination of Discrimination against Women (CEDAW) and the Convention on the Rights of the Child (CRC) of 1990 (Rana & Koirala, 2021; United Nations Population Fund, 2017). The constitution of Nepal includes SRHR of sexual minorities (Dhakal, 2023). SRHR encompasses healthy sexuality and reproduction, including the right to sex education, freedom from sexual assault and coercion, and the freedom to choose whether to have children. Universal access to SRHR is critical for sustainable development and addressing the needs and aspirations of people worldwide, including minorities and those with Autism Spectrum Disorder (ASD) and Intellectual Disabilities (ID).

Comprehensive Sexuality Education (CSE) is considered an effective approach to addressing the issues affecting adolescents (Aryal et al., 2023), however, the lack of understanding of adolescents as sexual beings significantly hinders the development of rights-based CSE (Braeken & Cardinal, 2008). Individuals with disabilities often face numerous obstacles when attempting to access sexuality education (Ubisi, 2021). People with disabilities deserve equal access to high-quality education, including CSE. Still, misconceptions and stigma hinder their access to sexual and reproductive health services (UNESCO Office Bangkok and Regional Bureau for Education in Asia and the Pacific & Leonard Cheshire, 2022). Neurodevelopmental disorders like ASD and ID require appropriate sexuality and relationship education, as they share similar desires and may face increased risk of exploitation and abuse (Sala et al., 2019). In addition, individuals with intellectual and developmental disabilities face increased sexually transmitted infection (STI) risk, higher abuse rates, and decreased sexual health knowledge,

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emphasizing the need for accessible and comprehensive sexual health education (Schmidt et al., 2020).

The policies of Nepal support inclusive education for learners with disabilities, but there is an observed implementation gap due to accessibility issues, inadequate teacher training, and insufficient resources. Teachers are not trained in CSE and traditional lecture methods, and negative social attitudes create complexities for effective teaching and learning (UNESCO Office Bangkok and Regional Bureau for Education in Asia and the Pacific & Leonard Cheshire, 2022). The problem remains in identifying and compiling health information by disability status in Nepal (Adhikari, 2019), resulting in adolescents and youth, particularly those with ASD and ID, being deprived of quality SRHR education.

This study is based on a human rights perspective on disability, guided by the Convention on the Rights of Persons with Disabilities (CRPD). Nepal is a signatory nation of the CRPD and ratified it in 2010. Article 25 of this convention guarantees individuals with disabilities the right to the highest possible standard of health without discrimination. It states, “Provide persons with disabilities with the same range, quality, and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs” (United Nations, 2007). It emphasizes how society contributes to the creation of disability and sees it as a human rights concern (Quinn & O'Mahony, 2017). Individuals with disabilities are entitled to the proactive enforcement of their rights by the government. A violation of these obligations is seen as a human rights violation.

However, our review—an early step of this study—revealed that there was no material regarding teaching sexuality education to children and adolescents with ASD and ID in Nepal, therefore, we decided to put a stepping stone in this area. The study aimed to support the creation of a teacher's resource booklet for teaching children and adolescents with ASD and ID focusing on CSE based on the suggestions of this study. The resource booklet is expected to help teachers and parents teach CSE contents, enabling children and adolescents with ASD and ID to make informed decisions about their sexuality, express their needs, and assert their rights, adhering to government standards and International Technical Guidance on Sexuality Education (ITGSE) 2018 guidelines (UNESCO, 2018). Given the context, this study aimed to analyze the international scenario of teaching sexuality education to children and adolescents with

ASD and ID and understand the expectations of parents and teachers, thereby preparing a CSE-resource booklet for the Nepalese context.

### **Methods**

We included an approach of integrating the bodies of evidence from the existing literature and primary study. Firstly, to understand the world scenario on the type of sexuality-related content included in the training manuals or curricula for adolescents with autism and intellectual disabilities, we searched and reviewed articles and manuals available in Google Scholar and PubMed keeping the keywords (in combination so far applicable): disability, intellectual disability, autism disability, ASD, sexuality, comprehensive sexuality education, CSE contents, and key concepts. After we identified the areas of sexuality education for these people, we discussed each area with the research team and with the officials of the Blind Youth Association of Nepal (BYAN).

We also sought information from the nine teachers and parents of adolescents with ID; and Eight teachers and parents of ASD regarding the sexuality content they expected to be provided to their students/children. The first author of the team conducted focus group discussions (FGDs) using a topic guide. In addition, two teachers and two parents of both categories of children/adolescents were interviewed using the interview guidelines. These were prepared beforehand and finalized in consultation with experts from the BYAN and Tribhuvan University (TU). We also conducted a series of meetings with BYAN and a comprehensive consultation meeting with the officials and experts from the Ministry of Education, Science and Technology (MOEST), Government of Nepal, developmental agencies and academia, and the teachers and parents of people with ASD and ID for the feedback on the contents of the teachers' resource booklet. This meeting discussed the contents to add or reduce in the resource booklet, the possible sub-contents to include, the outline, methodologies on the contents for adolescents with autism and intellectual disabilities, and any other feedback. Finally, we assembled all the insights from the review and the discussions, interviews, and consultations, and selected the main areas of sexuality education seemingly important in the Nepalese context.

### **Results and discussion**

This section incorporates results obtained from both the literature review as a secondary source and field data as a primary source.

### **CSE contents for children and adolescents with ASD and ID in different countries**

The education systems of many countries lack focus on sexual health and well-being for children and adolescents, with accessibility concerns arising when students with disabilities participate in CSE. A comprehensive review of literature from 1995-2015 on sexuality education for individuals with ID found that inadequate education increases the risk of sexual abuse, STDs, and misinformation (McDaniels & Fleming, 2016). The study concluded that formal, individualized, and specific sexual education is lacking, and suggested changes to the current approach due to the lack of published data. Similarly, the sexual development of youth with ASD is hindered by a lack of knowledge and social difficulties, necessitating early access to basic sexuality knowledge to prevent inappropriate behaviors (Picard-Pageau et al., 2024).

A Norwegian study revealed knowledge gaps in participants regarding female genitals, hygiene, appropriate sexual acts, and contraception, highlighting the potential impact on their sexual health (Svae et al., 2024). The United States curriculum covers sexuality education for children and adolescents with developmental disabilities, covering topics such as body changes, adulthood, social skills, dating, and physical or sexual abuse, among others (Baxley & Zendell, 2005). A study found that despite positive beliefs about the sexuality of autistic youth and support for CSE, school-based occupational therapy practitioners (SBOTPs) in the United States do not currently teach most key concepts and have limited materials and tools to teach sexuality to autistic youth (Bailey & Talero Cabrejo, 2024). This suggests a need for capacity development activities for OT practitioners.

Despite recent changes in sexual health curricula, there is a lack of emphasis on the sexual health and well-being of children and youth with ASD in Canadian school settings. Recommendations include more inclusive approaches in areas like puberty, relationships, and gender and sexual diversity that can help them understand their body's sexual feelings and ease conflicting messages about their sexuality (Davies et al., 2022).

In Malaysia, a training module is designed for caregivers of children and adolescents with disabilities to equip them with the necessary knowledge and skills about sexuality, personal care, and safety (Family Health Development Division, 2009). In Mongolia, the mainstream health education curriculum integrates eight key concepts of CSE, but children with disabilities are less likely to attend mainstream schools. Accessibility issues arise when learners with disabilities are exposed to CSE. Teachers

receive pre-service and in-service training but do not cover disability issues. Special education schools often remove certain sexuality topics due to teachers' difficulty, therefore, the teachers need support with disability-specific teaching resources and CSE teacher training (UNESCO Office Bangkok and Regional Bureau for Education in Asia and the Pacific & Leonard Cheshire, 2022). Positive attitudes toward sexuality education are observed among learners, parents, and teachers, but conservative attitudes toward discussing sexual issues need to be addressed.

The Philippines has a rights-based view of disability since the Magna Carta for Persons with Disabilities, and sexuality education is legal, however, disability is superficially covered, and policy guidelines do not mention crucial sexual topics (UNESCO Office Bangkok and Regional Bureau for Education in Asia and the Pacific & Leonard Cheshire, 2022). A systematic review of peer-reviewed articles from 1980-2018 analyzed sexuality and relationship education programs for individuals with ID and ASD. Thirty-three studies found that content primarily focused on biological content and self-awareness/safety rather than personal sexuality and relationships (Sala et al., 2019).

A scoping review of six studies examined sexual health education interventions for individuals with intellectual and developmental disabilities aged 15-24 and found that the studies covered topics like puberty and healthy relationships (Schmidt et al., 2020). Another literature review on sexuality in intellectually disabled individuals suggests personal and family education on anatomy, body functioning, abuse, contraceptive use, and sentimental relationships, highlighting the importance of sexuality education (Medina-Rico et al., 2018). An umbrella review of systematic reviews of relationships and sexuality education programs for people with ID identified four themes: biological information, personal sexuality, personal relationships, and self-awareness and safety (Pérez-Curiel et al., 2024).

These themes cover basic anatomical differences, personal hygiene, life cycle, sexuality, family planning, avoiding pregnancy and STDs, and social boundaries and abuse prevention. Numerous reviews demonstrate how insufficient sexuality education raises the risk of sexual abuse, STDs, and misinformation for people with ASD and ID. Unfortunately, access to this education is either too restricted or nonexistent in many nations. The primary goal of the literature study was to identify the CSE content coverage for individuals with ASD and ID. This process also assisted us in obtaining the

information we needed from parents and teachers of children and adolescents with ASD and ID.

### **Expected CSE contents for children and adolescents with ASD and ID in the Nepalese context**

The field data obtained from FGDs and interviews focused on the physical, mental, and social changes observed in the child's development, sexual behavior, and the effects of these changes. The participants discussed what they found admirable and problematic sexual behaviors, and what kind of education should be provided to help them understand the changes and effects of adolescence. They also discussed the key subject knowledge and skills to teach to adolescents with learning difficulties, and the methods and ways to ensure they can learn these topics effectively.

#### ***Human body***

Most parents and teachers said they faced problems while teaching their children about their body organs. Every human has a unique body type and potential (Crawley et al., 2008), and individuals must understand the difference between public and private body parts and activities (Tissot, 2009). Therefore, children with ASD and ID should be taught about public and private body parts and spaces. Since, this can be achieved by discussing body parts like nose, eyes, ears, hands, and feet while bathing and identifying private parts like penis, testicles, vagina, and breasts, the first session of the booklet includes these. Similarly, discussing private parts when changing clothes can help children identify their private parts. Using correct language and names is essential for children with ASD and ID, as they may struggle to express pain and abuse due to a lack of vocabulary. Teaching them the right vocabulary, especially about private parts, can help them communicate effectively and report physical and sexual abuse.

#### ***Violence and the good and bad touch***

Parents and teachers were concerned over the prevention of their children from violence, particularly that of a sexual nature. Children and adolescents with ASD and ID are often targeted for abuse and sexual violence due to their inability to recognize and respond to their behavior (Edelson, 2010; McDonnell et al., 2019). Violence originates from a bad touch and is prevalent across all socioeconomic levels, ethnic and cultural backgrounds, religions, and individuals (Puspitasari et al., 2019). This issue arises from a lack of education about the behavior being done to them, which is not addressed by



families and schools. Since sexual and reproductive health education is also a right for these children and adolescents, this is included in the second session of the booklet.

### ***Adolescence***

Parents believed that their children and adolescents with ASD and ID experience similar changes as normal individuals, with the pace of development varying. It is crucial to educate adolescents about their bodies and sexuality to help them accept these changes with a positive attitude (Ballan & Freyer, 2017). Lack of information, social experiences, and sexuality-related knowledge can make these changes seem challenging. Adolescents with ASD and ID often face developmental tasks primarily focusing on self-concept and social identity (Morgan, 2023), they often compare themselves to others, experience self-consciousness about their appearance, and sometimes experience shame, and exhibit increased avoidance and withdrawal (van Trigt et al., 2023). The third session of the booklet aims to emphasize the uniqueness of each individual and the varying rates of adolescent changes.

### ***Menstrual hygiene management***

Parents of ID were more apprehensive about teaching their girl child about menstruation and its hygiene management. Teaching children with ASD and ID about personal hygiene and using toilets in needful conditions is crucial for independence (Piccin et al., 2018). Menstruation is a natural process, but many adolescents struggle with it, leading to social confusion in Nepal (Bhattarai et al., 2020). Adolescent girls with ASD also often struggle with proper self-care and menstrual hygiene (Arslan et al., 2024). On the other hand, right nutrition and cooperation are also essential for clean and healthy menstruation. Similarly, adequate hygiene of reproductive organs, and the whole body, and regular physical exercise can help make menstruation a wholesome experience. The fourth session of the booklet contains all of these items.

### ***Relationships and responsibilities***

Parents in the discussion revealed that children and adolescents with ASD and ID often face problems in maintaining healthy relationships and understanding their limitations. Individuals with ASD and ID may struggle with understanding healthy boundaries in traditional social relationships and different types of relationships due to limited experience (Webster & Carter, 2007). These people frequently encounter stigma and obstacles in forming intimate romantic relationships (Sala et al., 2019). They may also struggle with grandparent-grandchild, sibling, and peer group relationships,



interrupting conversations, waiting their turn, entering rooms without knocking, and taking belongings. Understanding this, the fifth session in the booklet includes the contents and activities of relationships and responsibilities.

**Public and private social behaviors**

Parents and teachers discussed the importance of teaching their children to understand and practice healthy behaviors in public spaces. Behaviors that can and cannot be done in private and public places are called private and public behavior. However, people with ASD and ID may not recognize these spaces and may exhibit private behavior even in public places (Mitter et al., 2019). Learning about these spaces helps children protect their safety and privacy, teach them how to conduct their activities, and develop knowledge of proper behavior in public and private. The sixth session of this booklet aims to enhance this knowledge to help children understand how to organize and follow boundaries in different spaces, giving them confidence and maintaining their independence.

**Skills for well-being**

Parents in the FGDs sought a kind of education that helps their children understand the need to say ‘No’ in specific situations and decide on their own on some sexuality-related issues. Adolescents, particularly those with ASD and ID, often struggle with different life skills (Behroz-Sarcheshmeh et al., 2017), limiting their ability to make responsible decisions and solve problems. These skills are crucial in surviving and protecting them from sexual abuse (Nyathi, 2022), particularly in Nepal, where many people are victims of harassment, abuse, and rape (Dulal, 2022). The seventh session in this booklet aims to impart information on consent, refusal, compromise, decision-making, and coping with negative influences to the parents and teachers of children and adolescents with ASD and ID.

Therefore, the following seven themes (main topics) and 19 sub-themes (sub-topics) to be included in the teachers' resource booklet emerged during the discussion with the teachers and parents of children and adolescents with ASD and ID on 29 March 2024 and the consultation meeting on 19 April 2024, and the comprehensive literature review:

**Table 1**

*Sessions included in the booklet*

SN	Main topics	Sub-topics
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1	Introduction to the Human Body	Introduction to body parts Introduction to genitalia Ways of self-care
2	Violence and Identification of the Good and Bad Touch	Introduction to good and bad touch Protection from bad touch
3	Changes during Adolescence	Introduction to adolescence Changes during adolescence Body image in adolescence
4	Menstrual Hygiene Management	Menstrual process Menstrual hygiene management
5	Relationships and Responsibilities	Meaning and types of relationships The role of adolescents in improving relationships
6	Public and Private Social Behaviors	Public and private places Public and private practices
7	Skills for Well-being	Giving consent Refusing (Saying No) Making agreement Decision making Coping the effects of peer pressure

It was revealed that different disabilities require varying approaches to provide information and knowledge. The development of accessible information requires careful consideration of language, images, audio, and video (Waight & Oldreive, 2024). For ASD, specific language is needed. For moderate ID, simplified language and signs are used. While profound ID focus on basic body parts is necessary, daily reinforcement of privacy rules, including keywords on communication devices is also essential.

### Conclusions

This article integrated information from the review of the literature as well as the discussion and interviews with the stakeholders to build a common understanding and use that in developing an action. We found that most of the reviewed literature in the international arena focuses on providing bodily information, appropriate sexual behaviors, relationships, safety, and hygiene. The focus group discussion and interviews with the teachers and parents of ASD and ID also revealed that along with knowledge of

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body changes and self-image, they need guidance on sexual behavior such as masturbation and public and private behaviors. Along with this, self-care, relationship identification and rational behaviors, preventing sexual abuse, and menstrual hygiene management were also expected topics.

The study emphasizes the importance of age-specific sexuality education (i.e. CSE) for children and adolescents, particularly those with ASD and ID, who are more vulnerable to sexual violence and lack sexuality-related information. The implications of this study include creating a teacher's resource booklet for teaching CSE to these children and adolescents, which will guide parents and teachers in teaching CSE both in and out of the classroom. This booklet can be used for classroom-based instruction or customized training for teachers and parents of children and adolescents with ASD and ID. Based on the findings of this study, we proposed creating a seven-themed CSE resource guide. This was the first booklet of its type; however, in the future, further research is needed to examine more topics to include in the booklet and meet the needs of the most disadvantaged children and adolescents with ASD and ID.

### **Declaration**

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The authors report that there are no conflicts of interest to declare.

#### **Authors' Contribution**

BA conceptualized the article, reviewed the literature, and carried out fieldwork. BA also communicated with the publication procedures. AA, NS, and SM provided scholarly

input and supported revising the article before publication. Each author provides consent for the publishing.

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