

## Sexuality in Adolescents with Intellectual disability: Felt Needs of Parents

Surekha Nair<sup>1</sup>, V. Indiramma<sup>2</sup>, Satish Chandra Girimaji<sup>3</sup>, Renjith R. Pillai<sup>4</sup>

<sup>1</sup>Social Worker, Illawarra Shoalhaven Child, Adolescent & Youth Mental Health Service Wollongong, NSW, Australia

<sup>2</sup>Associate Professor (Retd.), Dept. of Psychiatric Social Work, NIMHANS, Bangalore, India.

<sup>3</sup>Professor & Head, Dept. of Child and Adolescent Psychiatry, NIMHANS, Bangalore, India.

<sup>4</sup>Assistant Professor, Department of Social Work, Central University of Kerala, India.

### ABSTRACT

**Introduction:** Felt needs of primary caregivers of adolescents with intellectual disabilities (AWID) with regard to sexuality issues has been an under researched area. The present study aimed to develop scientific knowledge in this area. This study gave a better insight into the less spoken area of sexuality among adolescents with intellectual disability, especially in the Indian context. **Methodology:** An exploratory design was adopted for this study which involved analysing the review of the literature, 20 unstructured interviews, 35 structured individual interviews, 10 key person interviews and 4 focus group discussions with 16 participants. **Result:** The specific concerns of parents with regard to educating sexuality issues of their Intellectually Disabled adolescents were identified. **Conclusion:** The findings emphasised the need for adequate knowledge attitude and practice among the parents in order to deal with the sexuality issues of adolescents with intellectual disability. This also laid the base for developing suitable tools and intervention program for this population.


**Keywords:** Adolescents, sexuality, intellectual disability, needs, parents

### INTRODUCTION

The sexuality of people with intellectual disability especially during adolescence has still been an under researched area, especially in the Indian context. The issues faced by the primary caregivers (referred to as parents in the current study) are often not explored or intervened unless there are inevitable psychosocial reasons due to which they are constrained to talk about it to a mental health professional. Most of these problems can be traced back to their sexual development during childhood and adolescence which are not paid attention

to at the right time. Parents often seek help when the behaviour gets out of hand or unmanageable. Most of the parents attending the mental health service express their inability to understand sexuality of their adolescent with intellectual disability and ways to define normal and deviant sexual behaviours. Also, there is difficulty in accepting the diagnosis of intellectual disability. The social stigma associated with Intellectual Disability is a high-stress factor in itself. An adolescent with an intellectual disability, like any other adolescent, is capable of having sexual feelings.

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**Address for the Correspondence :** Dr. Surekha Nair, Social Worker, Illawarra Shoalhaven Child, Adolescent and Youth Mental Health Service, 1-5 Atchison Street, Wollongong, NSW-2500. Email: surekha79@gmail.com

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However, this is often not acknowledged or supported by the care givers. While an adolescent with intellectual disability may present to the mental health service with multiple issues, it is important to assess and include sexuality as one of these needs.

Individuals with intellectual disability are dependent on their parents for most of their lives. Hence they are indispensable when it comes to working with them. The needs of the families having a child with an intellectual disability are very complex and call for developing support programs for these families.<sup>[1]</sup>

It is very important for mental health professionals and sex educators to work closely with the primary caregivers of persons with intellectual disability for their intervention to be successful.<sup>[2]</sup>

Needs of parents of children with intellectual disability have been studied by a number of researchers. They have been found to be very complex and hence call for developing support programs for these families.<sup>[1]</sup> They are also unique to every person and family.<sup>[3]</sup> It has been noted that parents who expressed more needs unrelated to their children were the ones who reported more issues in terms of lack of time or energy to follow up on the interventions advised to them.<sup>[4]</sup> Hence understanding the needs of the families is very important to ensure effective interventions and follow up. It is always beneficial to address what the family needs at the outset before planning the management strategies for the child.<sup>[5]</sup>

Eastgate et al.<sup>[6]</sup> had focussed group discussions among parents of individuals with intellectual disability. The major themes that emerged during the discussions included views on sexuality and intellectual disability, consent and legal issues, relationships, sexual knowledge and education, disempowerment, exploitation and abuse, sexual health and parenting.

The needs and goals for families with children with intellectual disability have been often determined by the professionals. Very few attempts have been made to understand the issue from the family's perspective and provide a need based intervention. This can be really counterproductive especially with regard to very sensitive issues like sex and sexuality. There have been studies which show that parents have an understanding

of the child's problems and are able to identify their specific needs with regard to child rearing.<sup>[1]</sup>

Needs expressed by the parents of the children with intellectual disability include: psychoeducation on diagnosis and management, support services available in their community in terms of day care, respite care and training, setting future goals,<sup>[7]</sup> vocational concerns,<sup>[8]</sup> support from other parents,<sup>[1]</sup> education, training, improving child's communication, better understanding of their child's legal rights.<sup>[9]</sup>

A few research studies have focussed mainly on other family members viz: siblings, grandparents rather than the parents of individuals with intellectual disability. Most of these studies focus on the attitudes towards the intellectually disabled child and the impact of family support on parental stress.<sup>[10,11,12,13]</sup>

There have been various studies in India which try to understand the felt needs of the parents of intellectually disabled individuals. The impact of having an offspring with intellectual disability on the parents was studied by Seshadri et al.,<sup>[14]</sup> Sequiera et al.<sup>[15]</sup> and Tangri and Verma.<sup>[16]</sup> There were also studies on treatment seeking behaviour of parents,<sup>[17]</sup> consumer demand for services by parents<sup>[7]</sup> and a conceptual framework for parent needs.<sup>[18]</sup> Rao (2008)<sup>[3]</sup> found that needs of the parents with children with intellectual disability varied between persons and also families. Parents have difficulties in managing the physical and financial demands of the intellectually disabled children which are often accompanied by problems related to loss of social support, compromising their careers and significant health issues.<sup>[19]</sup>

Accommodation, respite, day programs and therapy are often prioritised by the families of persons with intellectual disability and the issues related to sexuality and relationships are not usually identified.<sup>[20]</sup> For caregivers of persons with intellectual disability psychosocial issues and access to services are the major focus of concern and take priority over sexuality and relationship issues of their ward.

In a recent study done by Sahay et al.,<sup>[21]</sup> the needs of parents of children with intellectual disability were examined under seven domains namely- family, social and professional support, information and financial

needs, child care, community services and explaining to others. Though this study focused on needs, it did not specifically address the sexuality issues.

Analysing information from the available research literature on assessing needs of families having individuals with intellectual disability<sup>[4]</sup> the following is strongly indicated: (i) If the needs are not met, this might interfere with the families adhering to the treatment regimen and benefit from the therapy. (ii) Unmet needs are positively correlated emotional and physical problems faced by the families. (iii) if there are more needs expressed by the families that are unrelated to the child, there is a high possibility of them reporting the lack of time, energy and resources to follow up with the interventions. (iv) Efforts to identify the felt needs of the families should precede professionally prescribed interventions.

Various psychosocial factors have been reported to impact the attitude of parents towards the sexuality issues of individuals with intellectual disability. These include personal characteristics such as age, educational attainment,<sup>[22]</sup> socio- economic status, and religion, the target of the attitude,<sup>[23,24]</sup> the gender, age and level of functioning of the offspring.<sup>[25]</sup> The attitudes and perceptions also varied depending on the socio- cultural environment.<sup>[26]</sup>

The sexuality of individuals with an intellectual disability is a highly challenging and sensitive subject, especially for caregivers.<sup>[27]</sup> Over the years there has been a gradual shift in the attitude of the society toward people with intellectual disability from being considered as 'asexual' or 'oversexed' to them as sexual beings and having sexual needs and rights.<sup>[28]</sup> However, caregivers tend to have a restrictive attitude toward their children with intellectual disability expressing their sexuality.<sup>[29,30]</sup>

Sexuality is one of 15 areas assessed using the NIMH Family Needs Schedule (parents version). This is an integral part of the NIMH need based family intervention model.<sup>[31]</sup> This model emphasises on having a good understanding of the health condition, behaviour issues, parental attitude towards sexuality and psychosocial background before undertaking any intervention in the area of sexuality issues of persons with intellectual disability.

A review of the literature, especially in India shows that there is a dearth of studies in this area. There is very less scientific information about the felt needs of parents with regard to the sexuality of adolescents with intellectual disability. The studies reviewed either focus on children or adults with intellectual disability. Most of the studies both Indian and Western regarding sexuality issues among persons with intellectual disability have been done among the adult sample.

This study aimed at understanding the felt needs of parents with regard to the sexuality of adolescents with intellectual disability. It involved analysing the review of the literature, unstructured interviews, structured individual interviews, key person interviews and focus group discussions. The main intention of this study was to lay the foundation for developing, implementing and evaluating an intervention program for the parents based on their felt needs and also to generate awareness regarding sexuality issues of adolescents with intellectual disability.

## METHODOLOGY

An exploratory design was adopted for this study. At the outset, the researcher had informal unstructured interviews with 40 parents of adolescents (aged between 10 to 20 years) with intellectual disability attending the outpatient department in the Child and Adolescent Psychiatry Unit at NIMHANS in order to get a first-hand knowledge and experience into the felt needs of the parents with regard to the sexuality issues of adolescents with intellectual disability. Based on this experiences the researcher prepared an Individual Interview Schedule for Parents (Appendix-A), Guidelines for Key Person Interview (Appendix- B) and Guidelines for the Focus Group Discussion (Appendix- C) in order to have structured and focussed interactions with the respondents. Then she interviewed another set of 35 parents of adolescents with intellectual disability individually during three months' (between July-September), who had come for consultation or follow up in Out Patient Department of Child and Adolescent Psychiatry Unit, NIMHANS. A semi structured interview schedule constructed by the researcher was used for this purpose. The schedule consisted of 17 questions, both open-ended and closed-ended. The key persons interviewed comprised of five special

educators, two psychiatric social workers, two Child and Adolescent Psychiatrists and one clinical psychologist who were experts in this field and had an experience working with the population with intellectual disability and their parents.

Out of the 35 who were interviewed individually, 16 agreed to participate in the focused group discussion. Four focused group discussions were conducted with four participants in each group. The researcher also conducted key person interview among ten professionals who had years of experience and expertise in dealing with the problems of parents of adolescents with intellectual disability.

**RESULTS**

As the study is exploratory and qualitative in nature, the data collected is at nominal and ordinal level. Hence the statistics used were descriptive. Following were the main findings of the study.

**Individual Interviews**

**Table -1  
Socio-demographic Profile of the Parents**

Category	f (N= 35)	%
Age of the respondent (in years)		
30- 35	20	57.1
36- 40	10	28.6
41- 50	5	14.3
Relationship with the AWID		
Mother	27	77.1
Father	08	22.9
Duration of stay with the AWID		
Since birth	33	94.3
Since 5 years	01	02.9
Since 10 years	01	02.9
Age of the AWID		
10- 14 years	18	51.4
15-16 years	13	37.1
18- 20 years	04	11.4
Sex of the AWID		
Male	16	45.7
Female	19	54.3
Degree of mental retardation		
Mild	20	57.1
Moderate	10	28.6
Severe	04	11.4
Profound	01	02.9

Out of the 35 parents interviewed, 57.1% of the parents belonged to the age-group of 30- 35 years and 77.1% of the respondents were mothers. The majority (94.3%) of the parents were living with the adolescents with an intellectual disability since childhood. 51.4% of the adolescents belonged to early adolescence, whereas, only 11.4% were in the late adolescent category. The gender-wise distribution of the adolescents with intellectual disability was almost equal with boys constituting 45.7% and girls constituting 54.3% of the sample. 57.1% of the adolescents were having a mild intellectual disability, whereas, the moderate, severe and profound categories constituted 28.6%, 11.4% and 2.9% respectively.

**Table- 2**

**Concerns shared by the Parents of the Adolescent Girls**

Issue	N= 19*	
	f	%
Fear of sexual abuse	19	100 .0
Personal safety	19	100 .0
Modesty	15	79.0
Menstrual care/ hygiene	12	63.2
Socialization	11	57.9
Aggression	8	42.1
Self care	6	31.6
Marriage	5	26.3

\* Totals is more than the number of respondents  
N= 19 due to multiple responses

All the parents (100%) of the adolescent girls with intellectual disability were concerned about sexual abuse (100%) and personal safety of their daughters. Other concerns shared by the parents regarding the sexuality and related issues of the adolescent girls with intellectual disability were modestly (79%), menstrual care/ hygiene (63.2%) and socialization (57.9%). Aggression (42.1%), self-care (31.6%) and marriage (26.3%) were also reported by the parents as areas of concern.

**Table- 3**

**Concerns Shared by the Parents of Adolescent Boys**

Issue	(N= 16)	
	f	%
Aggression	10	62.5
Vocation	9	56.3
Hygiene	9	56.3
Self care	8	50.0
Masturbatory practices	5	31.3
Sexual advances towards opposite sex/disinhibition	3	18.8
Marriage	3	18.8

The major concerns shared by the parents regarding the sexuality and related issues of the adolescent boys with intellectual disability were aggression (62.5%), vocation (56.3%), hygiene (56.3%), self-care (50%) and masturbatory practices (31.3%). Other concerns included sexual advances towards opposite sex/ disinhibition (18.8%), and marriage (18.8%).

**Table- 4**

**Parental Attitude towards Sex Education**

Statements	Response (n= 35)			
	Yes		No	
	N	%	N	%
Concern about future of adolescent's sexuality	35	100.0	--	00.0
Instructions provided regarding Sexuality	2	05.7	33	94.3
Responsibility of sex Education should be taken by				
Family	33	94.3	--	00.0
School	0	00.0	--	00.0
Both	2	05.7	--	00.0
Ideal age to start sex education				
Adolescence	25	71.4	--	00.0
As and when need arises	7	20.0	--	00.0
Early childhood	3	08.6	--	00.0
Need for training about providing sex	35	100.0	--	00.0

All the parents (100%) had concerns about the future in terms of the adolescent's sexuality. Majority of the parents (94.3%) were never provided with any instructions regarding sexuality issues. 94.3% of the parents felt that sexuality education was solely the responsibility of the family whereas only 5.7% felt that this was a shared responsibility of the family and the school. The ideal age to start sex education was during adolescence as per 71.4% of the parents whereas 20% opined that it should be done as and when the need arises and only (8.6%) said that it should be started at early childhood.

**Key Person Interviews**

The following were the main issues derived from the key person interviews:

1. The topic selected for the research study is a very challenging one as it is a very sensitive issue.
2. The issues among the parents of the adolescents with intellectual disability to deal with the sexuality issues of their children:
  - a. Lack of sense of modesty
  - b. Adolescent issues: anger outbursts, demanding/ oppositional behaviour etc.
  - c. Menstrual hygiene
  - d. Masturbation
  - e. Lack of understanding about adolescent development
  - f. Lack of self-help skills
  - g. Concern regarding sexual abuse. Especially among parents of adolescent girls.
  - h. Lack of confidence to address sexuality issues
  - i. Burnout due to caretaking burden among parents
  - j. Lack of knowledge about psychosexual development of adolescents with intellectual disability among parents
  - k. Lack of awareness about sexual health issues among parents
  - l. Lack of awareness among the parents about sexuality rights of adolescents with intellectual disability
  - m. Stigma and embarrassment associated with sexuality issues that prevent the parents to discuss their problems openly

3. Major areas to be focussed during need assessment were:
  - a. Parental knowledge about various aspects of sexuality among the adolescents with intellectual disability
  - b. Parental attitude towards sexuality issues the adolescents with intellectual disability
  - c. General practice among parents with regard to the sexuality issues the adolescents with intellectual disability
  - d. Sexuality rights of the adolescents with intellectual disability.
  - e. Support system to deal with the sexuality issues the adolescents with intellectual disability
  - f. All the components of sexuality including self-care, gender role functioning, reproductive health, expression of sexuality, marriage, heterosexual relationship, felt need and readiness for sexuality education etc must be included.
4. The approach of the interviewer should be non-threatening, supportive and non- directive. The questions should be asked very objectively and scientifically to avoid embarrassment for the parents while answering to sensitive issues on sexuality. The parents should be allowed to ventilate their emotions if they feel the need to do so during the sessions.
5. It is a relatively new area. So every step should be taken only after proper groundwork. Parents should be provided scientific and accurate information.
6. Parents are less likely to be open about the sexuality issues of their child with an intellectual disability unless proper rapport is built. Some may be guarded despite our best efforts. The data has to be taken at face value as given by the parents.
7. Parents who express significant problems should be provided with appropriate psychosocial interventions and support.

### Focus Group Discussions

A total of four focused group discussions were conducted. Group one consisted of three mothers and one father, group two consisted of four mothers, group three and group four consisted of two mothers and two fathers each. In total mothers of six adolescent boys and five adolescent girls with intellectual disability and fathers of four adolescent boys and one adolescent girl with intellectual disability were a part of the focus group discussions.

#### *Themes derived from focus group discussion transcripts*

Discussions with the parents revealed the following concerns which pertained to the area under study:

1. The sense of inadequacy in dealing with the issues related to the sexuality of the adolescents with intellectual disability.
2. Significant distress related to adolescent issues.
3. Discomfort in addressing the issue in order to seek help.
4. Parents have not yet approached any professional help.
5. Distress in dealing with normal sexual development among the adolescents with intellectual disability.
6. Poor knowledge about normal sexual development.
7. No idea of what to expect in a sex education package.
8. Poor knowledge about sexuality issues.
9. The major concerns were a personal safety against sexual abuse and social role functioning followed by inappropriate expression of sexual feelings.
10. All the parents felt the need for sexuality education.

Some verbatim reports of issues discussed in the focus group are as follows:

*"I am scared to leave my daughter alone at home. I am not able to attend any social functions..."*

*"I don't know how to broach the topic of sexuality with my child. I don't know whether he/she would even understand..."*

*"I am concerned whether my child would be able to get married in future. We don't want her to be left alone to us..."*

*"I have never thought of this topic (sexuality) as I consider that it is not relevant to my child...."*

*"My child is very naïve. I am concerned about him being misled by bad company... Drugs, alcohol etc...."*

*"My other children picked up the knowledge regarding sexuality.... I did not have to explain a lot of things they know.... But with this child, I have to teach him everything as he has no other means of knowing about it...."*

*"I don't think I need to talk to my child about these (Sexuality) things as I don't think she would understand. I don't want her to get new ideas. And I monitor her all the time...."*

*"I have taught my daughter not to allow anyone to touch her. A few days ago she slapped her father when he got close to her. I am glad she did that. At least I am assured she would be safe....."*

## DISCUSSION

The analysis of literature revealed that there is a scarcity of literature in the Indian context and worldwide. The needs assessment was carried out for the main purpose of understanding the felt needs of the parents with regard to issues of sexuality among adolescents with intellectual disability and their perspective of how it impacted their lives.

It was noted that there were differences in the needs expressed by parents of girls and boys with intellectual disability. Similar findings have been noted by other studies.<sup>[32,33]</sup> All the parents were concerned about sexual abuse and personal safety of their daughters its corroborated with previous findings. All the parents had concerns about the future in terms of the child's sexuality. This finding is on par with other studies where parents of individuals with intellectual disability are reported to be highly concerned regarding their child's sexuality issues. They have been showing high levels of anxiety and fear around their child's sexual ignorance which is a risk factor for sexual exploitation and inappropriate sexual behaviour.<sup>[33]</sup>

A vast majority of the parents (94.3%) were never provided with any information regarding sexuality issues. This is supported by the study done by Karellou parents were reluctant to share information regarding sexuality to children as they themselves have misconceptions and fear that children may show erratic thoughts and behaviours that could be difficult to handle. Hence it is understandable to see only a small numbers of parents discussing such matters with their children with intellectual disability in the past. But there are other studies which contradict this by saying that parents have favourable attitudes toward sex education for their children with intellectual disability as they believe it would ensure safety against sexual abuse.<sup>[24]</sup>

Most of the parents (94.3%) felt that sex education was solely the responsibility of the family whereas the rest 5.7% felt that this was a shared responsibility of the family and the school. On par with the above findings of the present study, it has been seen that parents, community leaders, educators and teens may find themselves at odds over information and attitudes they consider appropriate. Parents and health care professionals are often pessimistic regarding the potential of children with disabilities to enjoy intimacy and sexuality in their relationships. People with disabilities are often erroneously regarded as childlike, asexual, and in need of protection. Conversely, they may be viewed as inappropriate for sex or as having uncontrollable urges.<sup>[34]</sup> McCabe<sup>[35]</sup> found that negative attitudes of caregivers toward the sexuality of individuals with intellectual disability invariably lead to the unmet need for sexual knowledge among these individuals. It was also observed that most of the sex education programs for individuals were focussed on providing information. Often, it was not based on their specific needs and there was no mechanism for evaluating the effectiveness of these programs. Parents generally have more conservative views regarding sexuality issues of their children with intellectual disability compared to support workers.<sup>[36]</sup> Younger parents tend to be less conservative in this regard.<sup>[37]</sup> Adults with an intellectual disability are likely to get confused due to these differences in views. The sexuality of persons with intellectual disability is often linked

with a sense of danger and the need to restrict or contain it and is not generally considered as something that needs to be nurtured<sup>[38]</sup>. Previous studies have found that parents have a favourable attitude towards providing sex education to their children with intellectual disability<sup>[23]</sup>.

One of the major concerns shared by the parents was fear of sexual abuse. Caregivers report significant issues with regard to sexual knowledge, relationship skills and self-protection skills, which is on par with previous findings,<sup>[39, 40, 41, 6]</sup>. Also, there was limited exposure of the persons with intellectual disability to potential relationship situations<sup>[42, 40]</sup> and inadequate social skills training.<sup>[43]</sup>

In this study, it has been reported that adolescence as ideal age for sex education 71.4% and 20% opinioned it is need based only 8.6% of parents have reported starting sex education in early childhood. This goes in line with a study by Tsutsumi<sup>[44]</sup> in which it was observed that according to 67% teachers and 48% parents, the adequate age was between 11 and 16 years.

In the present study, it was observed that almost all the parents thought about sex education only when they observed any undesirable sexual behaviour in the intellectually disabled, especially during adolescence. Till then they do not bother about the sexuality issues of the adolescent with intellectual disability. It has been studied that caregivers have reported having poor understanding regarding their children with intellectual disability in the areas of sexually transmitted infections, sexual health, safer sex practices legal issues and contraception<sup>[45]</sup>. Issues related to sex and sexuality generates discomfort among the parents.<sup>[46, 6]</sup>

The process of the study and the experience gained was equally important as the information gathered from the respondents. It was encouraging to see the respondents expressing their apprehensions toward this sensitive topic. The impact of engaging them in a therapeutic professional relationship was also seen. Development of Individual Interview Schedule for Parents, Guidelines for Key Person Interview and Guidelines for the Focus Group Discussion in order to understand the felt needs of the parents with regard to the sexuality issues of adolescents with intellectual disability can be seen as a

significant contribution to the present study. The respondents were provided psychosocial interventions for the problems faced along with scientific knowledge regarding the sexuality of persons with intellectual disability.

## CONCLUSION

This study contributed to the growing evidence based knowledge about the felt needs of the parents with regard to the sexuality of the adolescents with intellectual disability. As sexuality is generally dealt only on a crisis level by the parents in the Indian context, such a study is helpful in taking a developmental and prevention approach in this area. This is a very sensitive area where the respondents had to be provided with scientific knowledge and constant support and reassurance throughout the process. The findings emphasised the need for adequate knowledge attitude and practice among the parents in order to deal with the sexuality issues of adolescents with intellectual disability. This also laid the base for developing suitable tools and intervention program for this population.

## LIMITATIONS

Though this study is a pioneering effort in understanding needs of parents with regard to the sexuality issues of adolescents with intellectual disability, it does have some limitations. Firstly, the number of participants is limited and hence it is not generalized. Secondly, the researcher had to take the response based on face value. Most of the participants had met the researcher only once or twice. This gave very little opportunity to establish a good rapport. So there might be a lot of information that would have been missed out because of that. Thirdly, the participants who agreed to participate in the study might have had more flexible attitudes toward sexuality of individuals with intellectual disability than those who declined to participate. There are shortcomings with regard to the methodology employed to ensure equal representations in terms of socio economic background and psychosocial factors. For example, the majority of the respondents were mothers. This is a common difficulty faced by researchers as fathers and other caregivers are underrepresented. This might be due to family structure



in India and similar cultures where child rearing is considered as women's role.<sup>[25]</sup> Further replication of this study in a larger sample that has a good rapport with the researcher is recommended. Also, a comparative study between parents and also between States would throw more light into this sensitive area. This study was done as an initial phase of the Doctoral study done by the researcher.

## APPENDIX

### Appendix- A: Individual interview schedule for the parents

Following were the main areas focussed during the individual interviews with the parents:

1. Modesty (inadvertently exposing themselves in public bathrooms/dressing rooms, adjusting underwear, stripping, etc.)
2. Masturbation in public / Masturbation at home
3. Menstruation
4. Participation in medical exams (pelvic exams, testicular exams, breast exams, etc.)
5. Pregnancy /Birth control
6. Sterilization
7. Wet dreams
8. Inappropriate touching of others (hugging or kissing strangers, touching another person's breasts or genitals, etc.)
9. Friendships /Heterosexual relationships
10. Marriage
11. Sexual abuse
12. Other \_\_\_\_\_
13. Are you concerned about the future in terms of your child's sexuality? Why or why not?
14. What instruction has been provided to your child related to sexuality? Was this provided by you or by a school program?
15. Do you think that sex education is the responsibility of the family, the school, or both?
16. Ideally, how early should sexuality education begin?
17. Do you need training about providing sexuality education for your child? Specifically, what topics most interest you?

### Appendix- B: Guidelines for key person interview

1. Opinion about the topic taken for the research study.
2. Needs observed among parents of the adolescents with intellectual disability to deal with the sexuality issues of their children.
3. Major areas to be focussed during the need assessment.
4. Approach to be taken while interviewing them.
5. Any other information that you would like to share in this regard.
6. Problems likely to be faced during the study.

### Appendix- C: Guidelines used for the focus group discussion

Following were the questions asked during the focused group discussion with the parents:

1. What do you think about the topic that has brought us here today (Sexuality and Intellectual Disability)?
2. In your family, who makes the decisions about the matters related to your child? (*Probe: father/ mother/ other relatives or elders in the family/ Others?*)
3. According to you, what are the problems you face as a part of your child growing up?
4. What are your major concerns as your child is growing up?
5. Have you sought any professional help to deal with the issue?
6. As a parent, how confident are you in taking care of your child's needs as he/ she grows up?
7. Do you feel the need of any help with regard to the problems you are facing? If so, Specify.
8. Let's summarize some of the key points from our discussion. Is there anything else?
9. Do you have any questions?

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