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ABUSE THREAT: PARENTS AS SEXUALITY EDUCATORS FOR ADOLESCENTS GIRLS WITH INTELLECTUAL DISABILITY.

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Abstract

While the issue of sexuality is often difficult for parents and professionals to discuss with children and youth, it is also one which is highly important to address in an open, frank, and matter-of-fact manner. Yet sexuality education is not something that is accomplished in a limited number of lessons parents deliver it is a lifelong process of learning about ourselves and growing as social and sexual beings. Because children and youth with disabilities will mature and one day be adults functioning within the community, they have a right to be fully and accurately informed about what sexuality means, what responsibilities it involves ,and what unique pleasures, joys ,and pain this aspect to identity can bring. The vast majority of patents want to be or already are the primary sex educators of their children.

The dangers of not providing children with developmental disabilities with sexuality education are serious and may result in self doubt, fear and embarrassment, unacceptable socio-sexual behaviors, social ridicule, unplanned pregnancy, and STI infections. Without sexuality education, children with developmental disabilities are precluded from reaching their sexual potential, and their continued ignorance makes them vulnerable to sexual exploitation. The goal is for parents of children with developmental disabilities to offer sexuality information from early childhood and to continue through adolescence, preparing their children to become sexually responsible and knowledgeable young adults. To accomplish this goal, parents need education and support from sexuality educators and family service providers on all sexual related education.

This presentation attempts to offer some need based practical suggestions to parents for how to take an active role in teaching mentally challenged adolescents about sexuality and safe guard their children from sexual perpetrators.

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Introduction:-

Sexual abuse is not a new phenomenon. Schechter and Roberge(1976) defined "sexual abuse as the involvement of dependent, developmentally immature children and adolescents in sexual activities they do not truly comprehend to which they are unable to give informed consent, or that violate the social taboos of family roles." The most comprehensive definition is given by the Standing committee on sexually abused Children, 1984 which states that, "Any child below the age of consent may be deemed to have been sexually abused when a sexually matured person has engaged or permitted the engagement of the child in any activity of a sexual nature which is intended to lead to sexual gratification of the sexually mature person."

The aim of the conceptual study is to find out the parents as sexuality educators for the adolescents with intellectual disability and role of parents in identifying the child sexual abuse and how to make them sexually responsible and knowledgeable youngsters. There are different forms of child sexual abuse include asking or pressuring a child to engage in sexual activities, indecent exposure of the genitals, female nipples, physical sexual contact with the child, or using child to produce child pornography. The effects of child sexual abuse can include depression, post traumatic stress disorder, anxiety, physical injury to the child; sexual abuse by a family member is a form of incest and can result in more serious and long term psychological problems. The modern concept of family relationships has changed and that has brought lot of changes. The concept of parent children relationship is getting worse in urban areas. Spending time with children has become a rare concept. To identify the parent's attitudes and how much they are aware of the sexual abuse evils, these can be known elaborately.

Prevalence Of Sexual Abuse In India:-

Nineteen percent of the world's children live in India. Growing concerns about female infanticide, Child marriage, child rapes and institutional abuse of children, caste system, discrimination against girl child, child labour and Devadasi tradition impact negatively on children and increase their vulnerability to abuse and neglect. Lack of adequate nutrition, poor access to medical and educational facilities, migration from rural to urban areas leading to raise in urban poverty. Children on the streets and child beggars are the result of broken families. These increase the vulnerability of children and expose them to situations of abuse and exploitation.

Sexual health is influenced by a variety of political and social events and is broader than the absence of disease [Edwards and Coleman, 2004], encompassing both mental and physical aspects of human functioning that are important to overall well being [Sandfort and Ehrhardt, 2004]. The concept of sexual health in persons with intellectual disabilities (ID) is an extremely sensitive subject, and while advances have been made in employment, housing, and other aspects of community integration, the sexual needs of these individuals have been relatively ignored or strictly controlled by caregivers and service agencies [Bambara and Brantlinger, 2002; Hinsburger and Tough, 2002].

The Importance of Sexual Health For The Intellectually Disabled:-

Sexual health for people with intellectual disability ID has received increased attention in the past several decades and was recently highlighted by the 58th World Health Assembly (World Health Organization [(WHO)], which urged member states to include a disability component, including those with ID, in sexual health policies and programs. Despite the heightened awareness of sexual health needs in this population, there has been a tendency to focus on issues of sexual rights and sexuality, and there is relatively less information.

Although people with ID are conceptually included in these goals, there exist few data on the sexual health of this population segment. Moreover, since services for people with ID are influenced by culture and vary greatly across countries, a uniform model for addressing preventive sexual health is inappropriate. Sexual hygiene (e.g., menstrual management), gynecological care, and sexual abuse will also be discussed because these are factors that have historically dictated sexual health practices in this population.

Other topics such as sexual well being (satisfaction, pleasure, dysfunction), relationships (consent, intimacy), body image, marriage/family, gender orientation, etc. are beyond the scope of this review and will not be addressed. A brief review of the history of sexual health in this population, as well as research on sexual activity, and knowledge, attitudes, and expectations toward sexuality will be included to create a broader conceptual framework from which to explore the main topics of interest.

Research has shown that these issues are unfounded and that individuals with intellectual disabilities have the right to and a need for sexual health education. That being said, there are still several barriers to achieving this goal.

Role of parents as educators:-

Parents and caregivers may be hesitant to bring up sensitive topics and do not know how to approach sexual health issues with their children. Thus, parents may ignore these topics altogether. They don't know how to express and in India it is a taboo, to talk on sex and sexuality to children.

Adolescents may have limited control over their sexual decision-making and it is worse among intellectually disabled children

The challenges associated with intellectual disabilities necessitate adaptations to traditional sexual health education programming and it is because they are excluded.

There is a lack of effective sexual health education programming available for adolescents with intellectual disabilities, meaning that the education they receive may not be appropriate to meet their needs.

Adolescents living with intellectual disabilities have sexual rights. These include the right to learn about their sexuality, the right to equality and non-discrimination, the right to receive sexual health information and education, and the right to the highest attainable standard of health. Research has shown that individuals with intellectual disabilities have the desire to learn about sexual health issues and often have engaged in sexual activities.

Research has also shown that a lack of sexual health education for adolescents with intellectual disabilities can result in a number of negative outcomes. These include:
A lack of knowledge of sexual health and healthy relationships and they are poor in understanding
An increased risk of victimization because of repeated abuse
An increased risk of unwanted sexual and reproductive outcomes (e.g., unplanned
pregnancy, sexually transmitted infections and other sexual problems.

- In contrast, parents to take up sexual health education for their own children with intellectual disabilities are associated with a number of positive outcomes. For example, education in this area can help to empower individuals with intellectual disabilities to explore their sexuality in positive ways, learn how to have healthy relationships, learn how to make their own decisions related to their sexual health, and reduce their vulnerability to sexual abuse.
- Education can also help to reduce inappropriate sexual expression. These findings highlight the importance of appropriate and effective sexual health education for this population. Need for Sexual Health Education for Adolescents with Intellectual Disabilities Adolescents with Intellectual Disabilities have Sexual Desires
- Like all adolescents, adolescents with intellectual disabilities experience significant physical, psychological, and sexual changes during adolescence. They have the same sexual needs and desires regarding their sexuality as people without disabilities.
- In a study of individuals with intellectual disabilities, participants across all age groups aspired to marriage and children in the future and thought that people with intellectual disabilities should not be prevented from having relationships,
- Adolescents with intellectual disabilities also engage in dating and sexual activity at similar or higher rates than other adolescents These needs and desires continue into and throughout adulthood, including the desire to form relationships, to engage in sexual contact, and to learn about sexuality and sexual health. Limited Knowledge regarding Sexual Health Like their non-disabled peers, adolescents with intellectual disabilities participate in sexual activities.
- However, without appropriate information and education, they are unable to do so in a manner that promotes their sexual health. A lack of effective sexual health education can negatively impact individuals with intellectual disabilities in adolescence and throughout adulthood. More specifically, a lack of such education may lead to a higher risk of negative sexual health outcomes (e.g., sexually transmitted infections [STIs] and unplanned pregnancies, Reproductive trac infections and higher risk of sexual abuse, and a lack of knowledge about healthy relationships. Sexual knowledge among those with intellectual disabilities is generally lower than those in the general population.

- This lack of sexual knowledge can lead to increased sexual risk-taking behaviours (e.g., not using contraception) and negative sexual outcomes such as unplanned pregnancies or the contraction of STIs. Incest is another aspect which the ID adolescents are unaware and be victims to them. Parents who are also contributors to it should be aware that it leads to negative outcomes from those children. These negative sexual outcomes are also more likely due to the fact that adolescents with intellectual disabilities may be less likely than other adolescents to use contraceptives, or prevent sexual assaults.

A study of adolescent and young adult American Indians with intellectual disabilities found that 38% had unprotected sex, 26% had unintended pregnancies, and 13% had three or more pregnancies because of sexual abuse. Adolescents with intellectual disabilities may not know how to use or negotiate contraceptive use, may have difficulty purchasing contraceptives and accessing sexual health clinics, and may not know about STIs or how to prevent them. Parents play an important role as sex educators, a parent should sensitize their child on this issues and sex education is an important intervention and counselling is a must also.

Research has also shown that girls and women with intellectual disabilities have additional risks due to a lack of education and awareness around sexual health. For example, the Canadian Cancer Society guidelines recommend regular pap smears (a cervical cancer screening test) for women who are sexually active by the time they are 21 years of age. Girls and Women with intellectual disabilities are seven to nine times more likely to have never had a Pap smear compared to women without intellectual disabilities. In addition, Girls and women with intellectual disabilities have been found to be at high risk for HIV infection, particularly due to their vulnerability to sexual abuse and limited access to sexual health education programs. Many of these women may be undiagnosed carriers of HIV as they may not know about, or where to go for, STI, Reproductive tract infections and HIV testing.

Limited Knowledge regarding Healthy Relationships, Although they report the desire for friendships, relationships, and marriage, those with intellectual disabilities may have difficulty in forming and maintaining such relationships. Many adolescents with intellectual disabilities may find social interactions challenging and may not know how to develop healthy relationships As such, adolescents with intellectual disabilities may experience loneliness and social isolation In a study of 38 neurotypical adolescents and 35 adolescents and young adults with Autism Spectrum Disorder (ASD), the findings indicated that individuals with ASD had less access to peers and friends, engaged in more unacceptable behaviours when trying to initiate romantic relationships, and persisted in trying to form these relationships even when the other party's disinterest was evident.

Building relationship and social skills are important aspects of sexual health education and can help adolescents navigate conversations about contraception, their feelings, and what they want out of relationships. Comprehensive sexual health education programs that include information and skills training on healthy relationships can be vital to increasing healthy peer relationships for individuals with intellectual disabilities. Such education programs could include information and training around starting, maintaining, and ending dating relationships.

Education and skills training relevant to sex refusal, resisting peer pressure, and communicating with sexual partners is also important to include Exclusion of Adolescents with Intellectual Disabilities from Sexual Health Education , Despite evidence that adolescents with intellectual disabilities have sexual desires and engage in sexual relationships, limited sexual health education has been offered to them.

Benefits of Sexual Health Education:-

Education is an important tool that can help to promote decision-making abilities in individuals with intellectual disabilities, helping to prepare them to make healthy choices. Comprehensive, appropriate sexual health education empowers individuals with intellectual disabilities to find sexual fulfillment while protecting themselves from abuse and unwanted sexual and reproductive outcomes (e.g., unplanned pregnancy, RTI, STIs,HIV/AIDS).

Sexual health education can reduce the risk of abuse in individuals with intellectual disabilities, can reduce inappropriate sexual expression, and can help teach the knowledge and skills required to start and maintain healthy relationships. As noted in the Canadian Guidelines for Sexual Health Education, the goals of sexual health education are "to help people achieve positive outcomes (e.g., self-esteem, respect for self and others, non-exploitive sexual relations, rewarding human relationships, informed reproductive choices) and to avoid negative outcomes (e.g., STIs/HIV, sexual coercion, unintended pregnancy.

Sexual health education is a right for all individuals and is an important tool for preparing all adolescents for future relationships and interactions.

Consent is a voluntary agreement to engage in sexual activity and is based on an affirmative standard (i.e., it must be a 'yes', not merely the lack of a 'no') Consent cannot be given by someone who is intoxicated, unconscious, or otherwise considered incapable of giving consent. Consent can be withdrawn at any time using words or actions. This means that people with intellectual disabilities may not be seen as having the capacity to consent to sexual activity. This can be problematic because it can prevent people with intellectual disabilities from fully controlling and expressing their sexual rights or preferences. It can also put those who have the authority to provide consent on their behalf (i.e., legal guardians or caregivers) in a powerful position . Thus, legal guardians and caregivers for people living with intellectual disabilities have a responsibility to balance the individual's need for protection with their need for control over the individual's sexual health. Caregivers or parents may also be worried about their liability in situations where they allow individuals with intellectual disabilities to engage in sexual activities and It can be difficult to determine whether an individual with an intellectual disability is truly consenting to sexual activity.

In healthcare situations what should be done:-

Several principles are used to determine capacity to consent.

- Firstly, capacity refers to mental ability to make a particular decision at a particular time.
- Secondly, capacity is not static but can change over time or require different abilities based on the nature and complexity of the specific treatment decision.
- Thirdly, assessed capacity can vary according to the supports provided. Fourthly, others who know the patient best should be involved to provide relevant information or to facilitate the person's understanding and communication.
- Finally, if the person is incapable of consent, a delegate for decision-making should be appointed; decisions should be based on the person's best interests in the current circumstances. It is important to give these individuals the knowledge and skills necessary to be able to make informed choices and advocate for themselves.

Abuse Individuals with intellectual disabilities are extremely vulnerable to sexual abuse and victimization. This vulnerability is due in part to their disabilities and in part to their lack of experience and education related to healthy sexuality. It is estimated that the risk of sexual abuse is 1.5 to 1.8 times greater for individuals with intellectual disabilities than their non-disabled peers. The social workers reported that many of the youth had histories of physical abuse, sexual abuse, and/or violence. They also reported that many of these youth often seemed to accept these behaviours as normal. It is difficult to know the true rate of abuse in this population as much abuse is unreported for a variety of Sexual Health Education for Adolescents with Intellectual Disabilities, to be frank many cases of sexual abuse are not reported and it is because they are intellectually they are not normal and they cannot identify the perpetuator.

Recommendations to the government of India:-

1. Prevention of disabilities
2. Inclusive education
3. Early detection and Intervention
4. Rehabilitation Measures
5. Providing special education
6. Development of professionals for Rehabilitation
7. Provision for assistive devices
8. Education and economic empowerment
9. Creation of barrier free environment social security.

Short term outcomes of parents as teachers include:-

1. Improve positive discipline techniques
2. A home environment conducive to healthy child development
3. More realistic expectations of age appropriate developmental milestones
4. There should be parent – child attachment
5. Reduction of stress

6. Fulfillment of basic needs

Some prevention efforts are provided through specifically designed programmes, other efforts are integrated into existeding school curricula. Some of the more common areas that prevention activities address or strength are:

1. Life skills training
2. Socialization skills
3. Problem solving and coping skills
4. Preparation for parenthood
5. Self protection training.

Conclusion:-

Like all adolescents, adolescents with intellectual disabilities have the right to sexual health education. In order for this education to be effective, it must be specifically designed to meet their needs. Sexual health education is important for reducing the risk of sexual abuse, STIs, and other unwanted sexual health outcomes in this population. It can also empower individuals with intellectual disabilities to explore their sexuality in positive ways, learn how to have healthy relationships, and learn how to make their own decisions related to their sexual health.

Adolescents with intellectual disabilities face several barriers to receiving appropriate and effective sexual health education. These barriers include the views of others around them, the lack of control that they face in their day-to-day decision-making, and the lack of adapted sexual health programming. These barriers must be addressed in order to improve the sexual health of adolescents with intellectual disabilities. It can be done only when the parents of these children become sex educators and lead them in the front.

The current literature search revealed no comprehensive, evaluated sexual health education programs for this population. However, there are some models and strategies available that can help guide education for adolescents with intellectual disabilities regarding their sexual health. The promising practice models include the Information, Motivation, Behavior (IMB) model, the Direct Instruction model, and using technology with the Computer-Based Interactive Multimedia (CBIM) model. Overall, these models highlight the importance of providing information and skill-building opportunities so that individuals gain knowledge and are able to put that knowledge into practice in real-world situations, again it can be done with parents as sex educators.

- People with intellectual disabilities often lack knowledge about what behaviours are appropriate and thus, may not recognize abuse when it happens.
- They may also lack the communication skills needed to report abuse.
- It can be difficult to report the abuse because the abusers are often in close proximity to the victim.
- Reporting of the abuse is often discouraged.

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