



CPRI

SEXUAL BEHAVIOUR TEAM

Promoting Safety and Sexual Health

Sexuality and Developmental Disability: A Guide for Parents

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This Package for Parents of Children and Adolescents with Developmental Disabilities Offers:

Information for you on what parents need to know, such as:

- *The parent's role;*
- *The facts about sexuality and developmental disability; and*
- *Suggestions for what parents can do.*
- *Tips and strategies for talking comfortably with your child about sexuality.*
- *Resource lists and links to gather more information.*

This information is a guideline only, as each child develops and becomes curious about sexuality at his or her own rate.

*****Choose the information that fits for you and your family values.*****

For Parents and Caregivers:

For some parents or caregivers of a child with a developmental disability, it can be difficult to think of your child as a sexual being. However, these children will go through pubescent changes and experience sexual feelings as they age chronologically. It is important that all children and youth, regardless of their developmental functioning or special needs, receive information about sex and sexuality. Sadly, individuals with special needs are at greater risk of being sexually abused, in part because of their own vulnerability. Education is vital regarding physical development and changes, hygiene, privacy, personal boundaries, and the difference between good touch and bad touch. As parents and caregivers, children's well being and safety needs to be a consideration at all times.

Some people think that if a child or adolescent with special needs is given information about sex and sexuality, it will then increase sexual interest. However, in most cases education is vital to help these children and youth understand their own bodies and feelings associated with sex and sexuality, and can save a child from embarrassment, humiliation and exploitation. They need information that is clear and concise and presented at their level of developmental functioning.

It is also important to be aware of other sources of information that may be detrimental to their understanding of healthy sexuality such as access to pornography or other sexually explicit media, pictures, movies, video games or television with sexually explicit content. It is difficult for children and adolescents to understand sexualized media as entertainment, and without education they may mistakenly believe that this information describes real life interactions without understanding the missing and critical elements of intimacy, closeness and romantic love. Share your values and beliefs about love, sex and sexuality with your child.

Parents Need To Know The PARENT'S role...

Parents can provide the guidance and knowledge their children need to become safe and happy adults. While parents take their responsibility for keeping their children safe from physical and emotional harm very seriously they are sometimes reluctant to talk about sexuality with their children because:

- They are uncomfortable talking about reproductive body parts and functions.
- They fear that talking about sexuality and reproduction will encourage their children to experiment.
- The fact is, many youth with developmental disabilities whose parents and caregivers discuss aspects of sexuality with them, are better prepared to protect themselves from abuse and make decisions about how they will express their own sexuality.
- They are not sure what their child needs to know. A common myth is that children and teens with developmental disabilities do not need to learn anything about sexuality because they will not develop into sexually mature adults.
- The truth is that all children are sexual beings from the beginning and will continue to develop socially and sexually throughout their lives.

As parents, you teach your children many things about sexuality and have since the day they were born. They learn from:

- the words that family members use (and don't use) to refer to parts of the body;
- the way they are touched by others;
- the way their bodies feel to them;
- what their family believes is okay and not okay to do;
- watching relationships around them.

They also pick up a great deal of information whenever they watch television, listen to music, talk with their friends and interact with the world around them.

The Adolescent & Teen with a Developmental Disability

Regardless of intellectual or physical limitations, generally between the ages of 9 & 13 children begin puberty. During this time they experience a great deal of change

physically, emotionally and sexually. There can be rapid bone growth, increased sexual drive and emotional ups and downs due in part to the uncertainty about what is happening to them.

- Following the rapid changes of puberty, adolescence begins. This time can be marked with conflict between children and their parents or caregivers. The conflict is often a result of normal adolescent need for more independence from the family.
- Parents make difficult decisions at this time about how much independence to allow their child. Based on your family beliefs and values and your child's ability, you will need to decide what you are comfortable letting your child decide for themselves. These decisions may include choice of clothing, hairstyles, friends and some activities that they do alone, such as visiting the doctor. These are all opportunities for your child to express themselves as individuals, separate from you.
- As your child sexually matures, there may be an increase in self-pleasuring behaviour. Generally, health care providers recognize masturbation as a normal part of development. Masturbation only becomes a problem if it is practiced in public or if the person causes physical harm to themselves.
- Reinforce concepts of "public" and "private".
- Help your adolescent understand that appropriate sexuality means knowing about and taking responsibility for sexual decision-making. By this stage your child should also have and understand information about sexual intercourse and other ways to express sexuality, birth control, condom use and disease prevention and the responsibilities of child-bearing.
- Teach the concept of Consent and emphasize that consent between two people about to engage in sexual relations is critical. If consent from both is not stated – then it cannot happen.
- Whether a child has a disability or not, the development stages will follow the same pattern at a slower or faster rate, until the child passes through puberty into adolescence until they become a sexually mature adult.
- Accept that even though your child may have a disability, all humans progress through the stages of social and sexual development to reach adulthood. Continue to have discussions with your adult children about the values that surround sexuality throughout the lifespan: intimacy, self-esteem, caring and respect.

Some FACTS about Sexuality and Developmental Disability...

- Among adults who are developmentally disabled, as many as 83% of the females and 32% of the males are the victims of sexual assault. (Johnson, I., Sigler, R. 2000. "Forced Sexual Intercourse Among Intimates," *Journal of Interpersonal Violence*. 15 (1)).
- The National Center on Child Abuse and Neglect has reported that children with disabilities are sexually abused at a rate that is 2.2 times higher than that for children without disabilities (Murphy, Elias, 2006).

- Victimization rates are ten times as high for persons with disabilities than for persons without disabilities (Modell, Mak, 2008).
- Although about 80% of women and 60% of men with developmental disabilities will be sexually molested by age 18, only 3% of their attackers go to jail (Hingsburger, Press Release CP Wire, May 2002).

What PARENTS Can Do...

According to David Hingsburger, an author and educator for 20 years who has worked with people with developmental disabilities who have been sexual victims or have victimized others, parents can:

- Protect their children by giving them correct information about sex and teach them to use correct language for their own body parts.
- Be certain their children understand and are aware of the concept of privacy.
- Teach about personal boundaries and when it is okay to say “no”. Often people with disabilities are taught to do as they are told but they need to know they have the right to non-comply when the boundaries are crossed. Hingsburger calls this the “ring of safety”.
- Ensure their children understand their personal rights and their choices for healthy sexuality.

Tips and Strategies

As a parent or caregiver, you are a vital link in providing your developmentally delayed child with sexual health education. This can be very difficult for some parents. The following are some tips that can help to make it easier.

1. **Plan Ahead** – Talk with your partner about the messages you want to give to your child, and clarify any issues before involving your child. It may also be helpful to consult with a health care professional who is knowledgeable about your child’s abilities and limitations. They may be able to help you sort out what and how much information will be beneficial for your child.
2. **Find Out What They Already Know** – It is possible that your child has been provided with some healthy sexuality education. Determine what they have learned and build on this. Be certain to correct any mis-information.
3. **Be Aware of Limitations** – As a parent, you know best your child’s ability to retain and apply learned information. Tailor the information and how it is provided to your child’s functioning level. Again your child’s health care support person may be a good resource.
4. **Be Consistent in Your Message** – To avoid confusing your child, be careful to give the same message each time.

5. **Use Repetition** – Repetition is an effective learning strategy for teaching concepts to a child with a developmental delay. Provide as many opportunities as possible for your child to assimilate information and test understanding. Capitalize on the every day activities such as dressing and bathing as opportunities for questions and answers.
6. **Be Clear and Consistent Regarding Public/Private** – Provide your child with a clear message about private and public parts and activities. Also, be certain to set limits on discussion about sex and sexuality. For example, questions about sex can be asked of parents, doctors, health nurses, etc, but sex is not a topic for the playground.
7. **React Calmly but Firmly** – Often parents are embarrassed by their children’s curiosity with their genitals, but it is important to avoid harsh reactions. Children can learn at an early age that there are private times and places to self explore such as a bathroom or bedroom. You can distract your child at other times and in places that are inappropriate. Discouraging self-exploration around others or in public places, while providing other times to be alone, teaches children early on about the concepts of “private” and “public.” Use easy to understand terms such as “being alone” and “being with others.”
8. **Teach the Difference Between Personal Boundaries with Family, Close Friends, Acquaintances and Strangers** – It is important for them to understand at a young age that their body belongs to them, and that they have a right to tell others not to touch them. As much as possible, encourage independence in bathing, toileting, and taking care of personal hygiene needs. Individuals with physical limitations are particularly vulnerable to exploitation; therefore, it is very important to discuss appropriate and inappropriate touch. Be certain to role model respect for appropriate boundaries in the home by knocking on closed doors, allowing privacy on the toilet or bath, and wearing a robe outside the bath or bedroom.
9. **Be Aware That You Are a Role Model** – Children learn much from what their families demonstrate on a day-to-day basis. In some homes, people choose to behave more formally with each other, while in others affection is freely shown with hugs and kisses. Be aware that these interactions are lessons your children are learning about how adults behave in close and personal relationships. Role model appropriate interactions and boundaries.
10. **Answer Questions** - Be calm in your response and use the correct terms for body parts. Treat their questions as you would any questions about how something works.

11. **Use Materials** – Utilize books and materials that are at a level you child can understand.
12. **Start Early** – The younger you begin to discuss/teach healthy sexuality, the more effective it will be. For example; talk with your child about private parts as soon as they are able to understand, and teach your child about puberty changes before they occur.
13. **Talk About More Than Just Sex**- There is much more to healthy sexuality than just sexual intimacy. Talk with your child about positive relationships, peer pressure, body image and responsibility.

Resource Lists and Links to Gather More Information. . .

CPRI offers a Family Resource Centre, located off the waiting room in the Crombie Building. The following resources that are of particular interest to parents of children with disabilities are available for borrowing:

Asperger's Syndrome and Sexuality - from adolescence through adulthood / by Isabelle Hénault ; foreword by Tony Attwood. --Philadelphia, PA : Jessica Kingsley, 1st American pbk. Ed. , 2006

Autism-Asperger's & Sexuality - Puberty and Beyond / by Jerry and Mary Newport ; foreword by Teresa Boluick. -- Arlington, Texas : Future Horizons, c2002.

Caution- Do Not Open Until Puberty! - An Introduction to Sexuality for Young Adults with

Disabilities / by Rick Enright; illustrated by Sara L. Van Hamme. -- London, ON : Thames Valley Children's Centre ; Carter's Printing of London, c1995.

I openers - parents ask questions about sexuality and children with developmental disabilities / by Dave Hingsburger. -- Vancouver, BC : Family Support Institute Press, c1993.

Teaching Children with Down Syndrome About Their Bodies, Boundaries, and Sexuality - a Guide for Parents and Professionals / by Terri Couwenhoven. Bethesda, MD -Woodbine House, 2007

The Facts of Life and More - Sexuality and Intimacy for People with Intellectual Disabilities / by Leslie Walker Hirsch. Baltimore, Paul H. Brooks Publishing Co. Inc, 2007

Also Check out:

Canadian Health Network (Canadian)

http://www.canadian-health-network.ca/faq-faq/sexuality_reproductive_health-sexualite_reproduction/8e.html

Articles about talking with your child/teen about sex; links to many resources, and guidelines for finding credible web sites.

The British Columbia Coalition of People with Disabilities (Canadian)

<http://www.bccpd.bc.ca/>

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This international organization works to facilitate full participation of people with disabilities in society and promotes independence. The AIDS & Disability Action Project (ADAP) helps to increase awareness among people with disabilities that they may be at risk. ADAP shares information about how to prevent HIV infection through educational and workshop materials appropriate for people with various disabilities.

Sexuality Information and Education Council of Canada (SIECCAN)

<http://www.sieccan.org>

SIECCAN is a national non-profit educational organization dedicated to informing and educating the public and professionals about all aspects of human sexuality. Browse through back issues of their journal to search for information on many topics related to human sexuality.

The National Information Center for Children and Youth with Disabilities (USA)

<http://www.nichcy.org>

An excellent website that provides well-researched and practical information to families and professionals about sexuality and disability. The website links to organizations, communities, recreational sites and other resources for people with disabilities.

Sexual Health Network (UK)

<http://www.sexualhealth.com/>

The Sexual Health network is committed to providing easy access to sexuality information, education, counselling, therapy, healthcare, and other resources for people with disabilities or illness. J: Sandra/parentpackageschildrendd05/09/01