

Sexuality and Developmental Disability: A Guide for Parents



calgary health region

Sexual & Reproductive Health
403-944-7115

This Package for Parents of Children and Adults with Developmental Disabilities Contains:

- ☺ Information for you on what parents need to know, such as:
 - The parent's role;
 - What sexuality is;
 - The facts about sexuality and developmental disability; and
 - Suggestions for what parents can do.
- ☺ Some questions you can ask yourself about what your family believes.
- ☺ Information about the stages of social and sexual development in children and teens.
- ☺ 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.****

Parents Need To Know

The PARENT'S role...

Parents want to provide the guidance and knowledge their children need to become safe and happy adults. Parents take their responsibility for keeping their children safe from physical and emotional harm very seriously however, are sometimes afraid of talking about sexuality with their children because:

- They are uncomfortable talking about reproductive body parts and functions. For many parents, the topic of sex was not discussed with adults when they were growing up.
- They fear that talking about sexuality and reproduction will encourage their children to experiment. The fact is, people with developmental disabilities whose parents and caregivers discuss all 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 children, teens or adults need 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 are already teaching your children many things about sexuality and have been since the day they were born. They learn from:

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

They are also picking up a great deal from outside the family whenever they watch television, listen to music, talk with their friends and interact with the world around them.

What SEXUALITY is...

Sexuality is not just sexual intercourse or sexual activity. Sexuality has to do with:

- being female or male, and how females and males are alike and different in the way they look and act;
- how we view our bodies and our relationships with each other;

- how we grow and change over the years;
- who we are as women and men (girls and boys); and
- how we reproduce.

Sexuality (our feelings and behaviours) is an important part of being human and **healthy sexuality** is an important part of a person's overall health and well being.

Adapted from: 1. Association for Sexuality Education and Training (ASSET). (1993). *Sexuality begins at home* (Brochure). Oak Harbour, WA: Author. 2. Sex Education Coalition. (1992). *Tips for parents* (Brochure). Silver Spring, MD: Author.

Some FACTS about Sexuality and Developmental Disability...

- The risk of being physically or sexually assaulted for adults with developmental disabilities is likely 4 to 10 times as high as it is for other adults (Sobsey, 1994).
- Children with any kind of disability are almost twice as likely to be sexually abused (Petersilia, 1988).
- Regardless of age, race, ethnicity, sexual orientation or class, women with disabilities are assaulted, raped and abused at a rate more than two times greater than non-disabled women (Cusitar, 1994; Sobsey, 1994).
- Women with developmental disabilities are more likely to be re-victimized by the same person, and more than half never seek assistance with legal or treatment services (Pease & Frantz, 1994).
- 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 call this the "ring of safety".
- Ensure their children understand their personal rights and their choices for healthy sexuality.

The following page of information was adapted from: Sex Education Coalition. (1992). *Tips for parents* (Brochure). Silver Spring, MD: Author.

As a parent, you hope that your child will always make good choices that are based on the values that your family shares. An important part of discussing sexuality with your children is sharing with them what you believe. YOU are an extremely important person in your child's life. Ask yourself:

- Does your child actually know what you believe?
- Have you really discussed your values about sexuality as a family?

The following chart may provide you with some things to think and talk about as a family. When you have a family discussion, remember to:

- Choose a quiet time when nobody is feeling rushed;
- Treat each other with respect;
- Really listen to each family member;
- Be honest; and
- Share the reasons for the things you believe.

What Does Your Family Believe?

Gender	Appearance	Relationships
<ul style="list-style-type: none"> ▪ What Does it mean to be male/female? ▪ How are males/females different? Alike? ▪ How are males/females "supposed" to act? ▪ Is there a double standard for males/females? Should there be? 	<ul style="list-style-type: none"> ▪ What is attractive? ▪ Do people have to be young to be attractive? ▪ What messages do you give in the way you dress? ▪ How do these messages affect your relationships with other people? 	<ul style="list-style-type: none"> ▪ What makes a good relationship? ▪ How are relationships different? (boyfriend, parent, child, business) ▪ How should people show affection? ▪ How can people resolve disagreements?
The Family	Sexual Communication	Life Choices
<ul style="list-style-type: none"> ▪ What makes a family? ▪ What rules does your family have about privacy? ▪ What responsibilities does each family member have? 	<ul style="list-style-type: none"> ▪ What attitudes do people have about: talking about sexuality? sexual slang? physical affection? ▪ Why do people often laugh and make jokes about sexuality? ▪ What is sexual harassment? 	<ul style="list-style-type: none"> ▪ What do people think about teens and: sexual behaviour? abortion? contraception? homosexuality? choices in adulthood (single, married, parenthood)?

Social and sexual development occurs together through interaction with the family and others. Learning about acceptable ways to behave socially is also learning to behave in sexually appropriate ways.

Stages of Social and Sexual Development in Children and Adolescents	Tips and Strategies for Parents and Caregivers
<ul style="list-style-type: none"> ▪ During infancy, healthy human sexual development is nurtured through the sense of touch, during rocking, feeding and being held. 	<ul style="list-style-type: none"> ▪ The love and warmth a baby feels helps them to develop trust and the ability to give and receive tenderness and affection in later life.
<ul style="list-style-type: none"> ▪ Toddlers are curious about their own bodies and many self-explore through masturbation. 	<ul style="list-style-type: none"> ▪ Often parents are embarrassed by their children’s curiosity with their genitals, but experts urge parents to avoid harsh reactions. Children can learn at an early age that there are private times to self-explore such as the bathroom or bedroom. You can distract your child at other times and 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 terms easier to understand such as “being alone” and “being with others”.
<ul style="list-style-type: none"> ▪ During the early childhood years children begin to learn about how people interact with each other by watching what happens between the people closest to them. Later on, their behaviours may reflect what has been modelled for them. 	<ul style="list-style-type: none"> ▪ 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.
<ul style="list-style-type: none"> ▪ In the pre-school and early school years, children generally begin to ask more questions and become more interested in the body differences of playmates of the opposite gender. The curiosity in their own bodies and the body differences of others is normal. They understand what it means to 	<ul style="list-style-type: none"> ▪ Answer questions calmly using the correct words for body parts. Treat their questions as you would any question about how something works. ▪ Use books and pictures for their level that your children will understand. ▪ If their curiosity leads to behaviour

<p>be male or female and begin to form ideas about gender roles.</p>	<p>that is socially inappropriate, correct the behaviour. Reinforce with stories that describe the use of more appropriate behaviours.</p> <ul style="list-style-type: none"> ▪ Teach your children the differences 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 the right to tell others not to touch them.
<ul style="list-style-type: none"> ▪ Through the early school years children either favour a social interest in the same gender or in the opposite gender. Both are normal. 	<ul style="list-style-type: none"> ▪ At this stage, activities and games with other playmates will help your children to develop in their social world. ▪ Give your children tasks at home that they are responsible for, and involve them in activities outside of the home to help build their self-esteem.
<ul style="list-style-type: none"> ▪ Generally between the ages of 9 and 13 children begin puberty. During this time they experience a great deal of change physically, emotionally and sexually. There is rapid bone growth, increased sexual drive and emotional ups and downs due in part to the uncertainty about what is happening to them. 	<ul style="list-style-type: none"> ▪ Before the changes begin, talk to your children about what they can expect to happen. Many books and videotapes are available (see resources listed) to help parents share this information in a way their children can understand. Knowing ahead of time what will happen can lessen fears and confusion, and help them to build confidence and a healthy self-image. ▪ Listen carefully to your children and allow them to express themselves and their feelings. ▪ Help your children to recognise their strengths, focus on them and develop them.
<ul style="list-style-type: none"> ▪ 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. ▪ As your child sexually matures, 	<ul style="list-style-type: none"> ▪ Parents make difficult decisions at this time about how much independence to allow their children. Based on your family beliefs and values and your children's ability, you will need to decide what you are comfortable letting your children decide for

<p>there may be an increase in self-pleasuring behaviour. The medical community and many religious groups, recognize masturbation as normal and harmless. Masturbation only becomes a problem if it is practised in public places or if the person feels guilty or fearful about the behaviour.</p>	<p>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 children to express themselves as individuals, separate from you.</p> <ul style="list-style-type: none"> ▪ Reinforce concepts of “public” and “private” and that appropriate sexuality means knowing the difference 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.
<ul style="list-style-type: none"> ▪ 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 and adolescence to become a sexually mature adult. 	<ul style="list-style-type: none"> ▪ 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.

Adapted from: National Information Center for Children and Youth with Disabilities (NICHCY). (1992). *Sexuality education for children and youth with disabilities* (Electronic Version). NICHCY News Digest, #ND17.

Resource Lists and Links to Gather More Information. . .

If not available from your local library, many of the resources listed **can be borrowed** free of charge from the **Vocational and Rehabilitation Research Institute (VRR)** or **Planned Parenthood Alberta (PPA)** resource libraries. To arrange a loan call:

- VRR at 284-1121. The loan period is three weeks. Resources available through VRR are noted with ***VRR** on the list.
- PPA at 283-8591. The loan period is one week. Resources available through PPA are noted with ***PPA** on the list.

Reading

Baladerian, N. J. (1999). **Abuse of Children and Adults with Disabilities: A Risk Reduction and Intervention Guidebook for Parents and other Advocates.** Mental Health Consultants

This book deals with the increased risk of abuse for people with developmental disabilities, the signs and symptoms of abuse, consequences of abuse and what can be done to lessen the risk of abuse.

Hingsburger, D. (1993). **IOpeners: Parents Ask Questions about Sexuality and Children with Developmental Disabilities.** Family Support Institute Press.

This book offers insightful and intelligent answers to real-life questions from parents, with the goal of teaching children with developmental disabilities about sexuality. The author has worked extensively with people with disabilities and he treats this subject not only with sensitivity but with good humour. *VRRRI
<http://www.cdss.ca/shop/itm00077.htm> (order information)

L'Institut Roehrer Institute (1990). **Shared Feelings: A Parent Guide to Sexuality Education for Children, Adolescents and Adults Who Have a Mental Handicap**

A guide to help parents of children with an intellectual disability discuss sexuality, STDs and sexual abuse with their children. Chapters include teaching social skills, talking to children about bodies and feelings, and making informed decisions.

<http://www.roeher.ca/Comersus/viewitem.asp?idproduct=57> (abstract and order information)

Our-Kids (Updated May 1, 1999). **Sexuality and Developmental Disabilities**

<http://www.our-kids.org/Books/sexed.htm> (full text)

A fact sheet contains statistics on the sexual abuse of women and girls with disabilities. A list of books and videos for parents and professionals deals with lessening the risk of sexual victimization and teaching people skills related to condom use and masturbation.

McKee, L., Blackledge, V. (1986). **An Easy Guide for Caring Parents: Sexuality and Socialization: A Book for Parents of People with Mental Handicaps.** Planned Parenthood.

This book addresses the social needs of children with mental disabilities. It also discusses the role of parents in their children's sexuality education. It includes a comprehensive discussion of sexual development and discusses such topics as growing up, responsible sexual behaviour, masturbation, social life, sexual orientation, fertility and birth control, sexual abuse, and marriage.

ISBN 0960689818

Melberg Schwier, K., Hingsburger, D. (2000). **Sexuality: Your Sons and Daughters with Intellectual Disabilities.** Paul H. Brookes Publishing Co.

Parents share the joys and challenges of raising a child with an intellectual disability and offer advice and practical strategies. Individuals with disabilities share what is important to them. *VRRl

<http://www.cdss.ca/shop/itm00078.htm> (description and order information)

Van Dyke, D. C., McBrien, D. M, Siddiqi, S. U., & Petersen, M.C. (1999). Sexuality and Individuals with Down Syndrome. In J. A. Rondal, J Perera, & L. Nadel (Eds.), **Down Syndrome: A Review of Current Knowledge**. London: Whurr. *VRRl

Audiovisual Resources, Audiocassettes, Parent Guides and Manuals

Agency for Instructional Technology and Planned Parenthood of Cincinnati (1987). **Sexual Abuse Prevention: Five Safety Rules from Persons Who Are Mentally Handicapped**.

The 24-minute video shows how to handle common situations such as going with a stranger, unwanted advances and inappropriate behaviours. Developed for people working with adolescents with disabilities. *PPA

Carmody, M. A. (1995). **Making Connections**.

A video that takes a humorous look at dating by and for persons with disabilities, drawn from their life experiences. Program Development Associates. *VRRl

Gray, J., Jilich, J. (1990). **Janet's Got Her Period**. James Stanfield.

This program is for girls and young women with severe developmental disabilities. Consisting of a video and an illustrated storybook with full-colour photographs, it tells the story of a young girl who learns menstrual self-care from her mother and sister. A teacher's guide is also included. *PPA

<http://www.stanfield.com/sexed-1.html> (description and order link)

Hingsburger, D. (1995). **Hand-made Love**. Eastman, PQ: Diverse City Press.

A book and video guide for teaching about male masturbation. *VRRl

<http://www.diverse-city.com> (description and order information)

Hingsburger, D. (1996). **Under Cover Dick**. Eastmen, PQ: Diverse City Press.

A book and video teaching men with disabilities about condom use. *VRRl

<http://www.diverse-city.com> (description and order information)

Hingsburger, D., Haar, S. (2000). **Finger Tips**. Eastmen, PQ: Diverse City Press.

A book and video teaching women with disabilities about masturbation. *VRRl

<http://www.diverse-city.com> (description and order information)

National Film Board (1992). **Toward Intimacy: Self-esteem, Sexuality and Love in the Lives of Women with Disabilities**.

A 62 minute video that looks at how 4 women with disabilities confront physical barriers and attitudes about their relationships. *PPA

Program Development Associates (1999). **All of Us Talking Together. Sex Education For People With Developmental Disabilities.**

This video is intended for adolescents and young adults with a developmental disability, parents, and health care professionals who work with the developmentally disabled. It presents young people's views on sexuality and parental concerns. It also addresses talking with children about sexuality issues, sexual abuse, HIV and has discussions between young people and health care providers about anatomy, contraception and STDs.

Siegel P. C. (1991). **Changes in You: The First Comprehensive Family Life Education Program for 4th – 9th Graders with Special Needs.** James Stanfield.

Provides a sensitive approach that helps girls and boys feel confident and comfortable with the physical, social and emotional changes during teen years. Included are easy to read books for independent use by students or as a resource for parents. *PPA

<http://www.stanfield.com/sexed-1.html#C> (description and order link)

James Stanfield (1990). **Being with People Series.**

An 8-part video series and teacher's resource guide. Demonstrations and scenarios are used to teach essential social skills to people with developmental disabilities.

<http://www.stanfield.com/life.html> (description and order link)

Walker-Hirsch, L., Champagne, M. P. **Circles I: Intimacy and Relationships.**

A program designed as a tool to teach about concepts of personal space, social distance and appropriate social/sexual behaviour in interpersonal relationships. James Stanfield. *PPA

<http://www.stanfield.com/sexed.html> (description and order information)

Walker-Hirsch, L., Champagne, M. P. **Circles II: Stop Abuse.**

A program designed to give people with developmental disabilities step-by-step lessons on how to recognize and avoid sexually threatening or abusive situations. James Stanfield. *PPA

<http://www.stanfield.com/sexed.html> (description and order information)

Walker-Hirsch, L., Champagne, M. P. **Circles III: Safer Ways.**

A program designed to give information to people with developmental disabilities about avoiding and treating communicable diseases and STDs/AIDS. James Stanfield. *PPA

<http://www.stanfield.com/sexed.html> (description and order information)

VRRI (1995). **Women's Resource Brochures: Going to the Doctor, Sexuality, Enabling Care.**

A 3-part audiocassette for women with disabilities includes information about doctor accessibility and procedures, talking and listening, sex, pregnancy, STD/AIDS, and birth control. Also, Information for health care providers about barriers and access to health. *PPA

Finding Resources in Your Community

Things to Think About

You may want to ask some questions to determine if an agency integrates a philosophy that provides a high quality of service and education that is appropriate for the age of your child, comprehensive, sensitive to your cultural beliefs and values, and respectful of individual choices and rights.

- What is the organization's philosophy and mission?
- What types of services do they offer?
- What type of training do the employees or volunteers receive?
- How are they funded and who are they accountable to?

Agencies That Support Sexual Health and Education

- The **Sexual and Reproductive Health Program** of the Calgary Health Region have an education team that provides inservices to parents, school and community groups, on many sexual health related topics. The education programs are provided free of charge. To arrange a program, or to request more information on a specific topic, call 944-7115.
- **Community Health Centers** have Public Health Nurses who are active within their communities and schools. They provide services, as well as information, counselling and referral regarding birth control, STDs, pregnancy options, and pregnancy and parenting. Some Health Centres may also have Family Planning and STD clinics. A listing of Community Health Centers in the Calgary Health Region is found in the pink pages at the front of the telephone directory. More information on services in the Calgary Health Region can be obtained by calling their information line at 943-LINK. Information on other Community/Public Health Units in Alberta's Regional Health Authorities is available by calling 1-800-432-1845, or through www.erc.calgary.ab.ca
- **Planned Parenthood Federation of Canada** offers services, information and counselling on sexual and reproductive health issues. To find a local affiliate near you go to www.ppfc.ca or call 1-613-241-4474. In Calgary, call 283-8591.
- **Calgary Birth Control Association (CBCA)** offers resources, counselling and education services for groups and individuals on many sexual health

related topics including birth control, pregnancy options and sexually transmitted diseases. Call 283-5580 or go to <http://www.cbca.ab.ca/>

- Your local schools provide sexual health teaching based on Alberta Learning's curriculum. The curriculum can be accessed through www.education.gov.ab.ca
- Your local community health centre may have a **Community Services Directory** (often available through the library) which will list community organizations, health and social agencies.
- Your community may have a **Family and Community Support Service** (FCSS) that may be able to direct you to other local agencies/resources, or help to set up local partnerships that focus on prevention and enhance social and health well-being.

Webliography for Parents

Links to web resources are provided for information only and do not imply an endorsement of views, products, or services. Although our staff regularly reviews these links, we can't be certain that they are 100% credible since their content can be changed at any time.

Calgary Health Region (Canadian)

<http://www.calgaryhealthregion.ca/hlthconn/hctopics.htm>

Information and pamphlets on a variety of sexual health topics and resources.

<http://www.calgaryhealthregion.ca/chr//srh>

An on-line mailbox for your questions about sexual health topics. Answers are posted within 1-2 weeks.

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.

Teaching Sexual Health Website (Canadian)

<http://www.teachingsexualhealth.ca/>

A sexual health website, based on Alberta Learning Curriculum, developed for classroom use by teachers. Includes sections for parents and students at all grade levels.

The British Columbia Coalition of People with Disabilities (Canadian)

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

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.

Sexuality and U (Canadian)

<http://sexualityandu.ca/eng/parents/>

Information about puberty, talking about sex with your child, STDs and contraception.

PFLAG (Parents, Families and Friends of Lesbians and Gays) (Canadian)

<http://www.pflag.ca/index2.htm>

Information, resources and support for parents of lesbians and gays.

Inner Learning Online (USA)

<http://www.innerbody.com>

Colorful anatomy pictures and text.

I Wanna Know (USA)

<http://www.iwannaknow.org/parents/index.html>

Information on being an “askable” parent, links to teen sites about puberty, STDs, abstinence, decision-making and condom use.

Kids Health (USA)

<http://www.kidshealth.org/parent/growth/index.html>

Articles on communication with your teen, puberty and surviving adolescence.

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

<http://www.nichcy.org>

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

Parent Soup (USA)

<http://www.parentsoup.com/teens>

A general parenting information site with sections on talking with your teen or preteen about sex.

Resource Center for Adolescent Pregnancy Prevention (USA)

<http://www.etr.org/recapp/practice/edskills200110.htm>

A teacher-based web site, which has a section on teaching students with developmental disabilities, that some parents may find useful.

Sexuality Education and Information Council of the United States (SIECUS)

<http://www.siecus.org/>

SIECUS is a national non-profit organization that develops, collects and shares information, promotes sexual health education and advocates the right of individuals to make responsible sexual choices. A section for parents includes information and links to many other resources. Go to

<http://www.siecus.org/pubs/srpt/srpt0031.html> for articles for parents about sexuality education 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.

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