

SEXUALITY: PREPARING YOUR CHILD WITH SPECIAL NEEDS



**HOW TO DEVELOP A PLAN FOR
SEX EDUCATION AND
SEXUAL ABUSE PREVENTION**

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Thanks,

Carl F. Calkins
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About the Authors

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Preface

Our national public policies are built on the principle that disability is a natural part of the human experience. So is sexuality.

As the mother of a young man who has developmental disabilities, like many parents before me and maybe like you, I kind of hoped we wouldn't have to deal with the topic of my son's sexual development. Let's just say that when a child has special needs, it is more difficult to discuss sexuality than it is when a child does not. And yet, however much more difficult it is, it is also that much more important.

It is comforting now to have this excellent guide available to help my family clarify our thoughts and direct our actions so that they will be helpful to our son and true to our family values.

I know this guide will be useful to many other families as well. If your family uses it, it will direct you to resources that already exist, and it will help you clarify your goals and develop real-world plans for supporting your child's healthy sexual development. There is excellent advice here, from people who have a deep understanding of our concerns. In fact, this book is one of the best examples I've seen of a powerful partnership between parental wisdom and professional knowledge.

A wise mother once said, "It is the duty of a parent to raise a child so other people will love him." We may

achieve this goal differently than many, but we should not abandon it just because our child has special needs. Everyone deserves to be loved, and healthy attitudes about sexuality are part of the mix. I hope you find joy and success in your efforts to raise your child so he or she will be loved, and I hope you find all the help you need along the way.

Sue Swenson
Commissioner
Administration on Developmental Disabilities
US Department of Health and Human Services

Introduction

Organization of the Book

This book is organized into five chapters.

Chapter 1 gives a brief overview of why a plan is needed and the importance of sexuality in a person's life.

Chapter 2 examines parental roles and critical choices that need to be made concerning the sexuality of their child.

Chapter 3 defines sexuality and sex education and discusses how parents can go about providing sex education to their child.

Chapter 4 discusses a basic approach to sexual abuse prevention.

Chapter 5 provides a format and suggestions on how to develop a sex education plan for your child.

SEXUALITY: PREPARING YOUR CHILD WITH SPECIAL NEEDS

HOW TO DEVELOP A PLAN FOR
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Overview

Why is this Book Needed?

Although there are many excellent resources in the field of disabilities and sexuality, a simple overview of information that will assist parents in making decisions about preparing their child with special needs for his or her sexuality has often been requested by parents. The need to develop this planning guide is emphasized by parents' great concern on how to go about preparing their child with special needs about sexuality. The concerns range from "should I address the issue at all," to "will information on sexuality put my child at risk," to "am I prepared to do this." The purpose of this book is to guide parents in developing a sex education plan for their child by answering the above questions, making informed choices and incorporating practical approaches into their everyday lives. Other care providers in the field may also feel similar responsibilities and this guide could assist them as well.

Nationally recognized sex educators state,

Whether we like it or not we as parents are the sex educators of our children from the time they are born. We teach our children about sexuality and behaviour [behavior] every day in an informal and incidental way. Children learn how to behave by observing their parents and by absorbing their parents' values. Despite all the information that can be obtained from a

group sex education lesson, children will invariably only accept that information which is consistent with their parents' values and behaviour [behavior]. Unless parents have been direct in their explanations, children may well misinterpret parental attitudes, especially when euphemisms and metaphors are used to deal with potentially embarrassing subjects. For children with intellectual disability, who may have difficulty understanding abstract concepts and symbolic representations, this can be even more confusing.¹

Further, individuals with special needs are at greater risk of sexual abuse and sexual misinformation; therefore, it is very important that they receive accurate and prompt information concerning sexuality in order to reduce the risk of sexual abuse. Everyone, both adults and children, can benefit from additional information concerning sexuality and sexual abuse prevention, and how to talk about it. It is important to acknowledge that even though this book is written for parents of children with disabilities, the basic approach is the same when preparing any child in sexual awareness and sexual abuse prevention.

Sexuality is an essential part of a person's life and lifestyle. Therefore, it should not be surprising that individuals with special needs have sexual feelings, needs and experiences. Like anyone else, people with special needs have sexual desires that are often associated with the needs for closeness, caring and emotional intimacy with other people.² Due to these

naturally occurring desires, it is important that children with special needs are given accurate information about human sexuality, sex and sexual abuse prevention. Accurate information will help shape their responses as they become capable, understanding and responsible sexual beings as adults. The dissemination of incorrect information can cause negative feelings about sex and in the worst case scenario may lead to compromising situations like unwanted pregnancies or sexual encounters.³

Therefore, it is important that sex education is provided to your child early in life in order to heighten self-confidence, increase self-esteem, alleviate misconceptions and fears around sexuality and empower them to make positive choices in their lives as adults. Many believe that informing their child about sexuality will promote poor choices in their exploration of themselves and others, when in fact, young people who have information about sex and sexuality will be better prepared to make good and informed choices.

The purpose of this book is to help you develop a plan to address your child's individual need for sex education. The following questions are designed to help you begin thinking about your plan. Please fill out the following as an initial effort (it's okay to write in the book).

- ◆ What are my views about sexuality and sexuality for my child?

- ◆ How would I approach preparing my child?

- ◆ Is sexuality something I am comfortable talking about with my child? If not, is there someone who could assist me?

- ◆ Do I know where to get the teaching materials I need to assist me?

- ◆ What goals would I like to see for my child in terms of preparedness in sexuality and abuse prevention?

Parents' Role and Critical Choices
When Talking to your Child with Special Needs

The overall role of a parent is to nurture growth and development throughout childhood. As a parent, you can assume many different roles in response to your child's sexual development. These include educator, confidant, role model, value setter, and, finally, protector. In carrying out each of these roles, it is important that you not only assess your level of comfort with this role, but your own knowledge, inhibitions and strengths. With this assessment there comes choices and challenges.

The role of a parent as a sex educator means that you may want to be prepared with more information, materials and an awareness of your child's sexual needs as he or she grows. The choices in relation to this role have to do with how and where to get information, as well as what information is appropriate. The challenges relate to when, where, and how to use this information.

The role of the confidant includes being a trusted and valued source of information for your child. It also implies that it is safe to come to you to discuss any topic that might be on the child's mind. Choices in this instance relate to willingness to hear and discuss topics that you may or may not be comfortable with, (e.g., your daughter may tell you about her friend who might be having sex). The challenge is deciding whether you are the appropriate person to deal with this subject.

The role of the model has to do with how you demonstrate to your child verbal or physical

expressions of sexuality. This could include the way you dress, or the way you relate to family members or to others in the community. In this role the parent also serves as a primary source of affection (e.g., expressing love by touching, cuddling, hugging, kissing, etc.). The choices in regard to being a role model have to do with family preferences, community norms and expectations within particular settings (e.g., church or school). Challenges arise when the parent's expectations differ from others that may have an influence in your child's life. For example, overnight parties and camping when both genders are invited.

In the role of a representative of morals, values, and ethics, there are considerable differences based on a parent's experiential, religious, and cultural background. Family preferences are the clear responsibility of the parent. Choices relate to understanding how values may be presented or accepted in differing environments. The challenges relate to willingness to tolerate or accept different value systems that your child may encounter. For example, what is an acceptable demonstration of affection in public can vary significantly among families.

In the role of protector the parent is concerned about any threat to the child's sexual being. This could include sexual abuse, AIDS, or something as simple as having the child's feelings hurt. Choices are evident as parents determine what level of involvement that they want, can, and should assume. In a perceived threat of sexual abuse, a parent may choose to monitor that environment and the individuals that the child may encounter, while another parent may choose to prepare the child to protect him- or herself in some of those

situations. Challenges for this role come with the fine line between direct intervention or preparation of the child to make responsible choices.

It is important to know that these roles overlap considerably with responsibilities, choices and challenges. The best basic guideline that should be followed relates to the choice of finding someone who could assume this role with your child if you are either uncomfortable or unprepared to do so yourself. The essential over-riding skills that support these roles include the ability to listen, be open and direct, be honest, and be an informed participant.

A Basic Approach

Thus, as parents, you have many roles and responsibilities when it comes to your children. Many critical choices are made on behalf of your children. One critical choice that you, as a parent, will need to make is whether or not you will take the sole responsibility of informing your child about sexuality and sexual abuse prevention, or will you seek additional help? Many parents are uncomfortable taking this role and may turn to counselors, teachers, or other professionals for assistance with this topic. Parents need to know that it is quite appropriate to get assistance, but the assistance should fit into an overall plan.

If you, as parents, take the role of providing sexual education to your children it is important that you first examine your own feelings, attitudes, values, morals, beliefs and comfort level related to sexuality issues and the sexuality of individuals with special needs. Make

sure that you have correct information before giving it to your child. It is okay to tell your child that you are not sure about an issue and that you will find out for him or her. It is also acceptable to tell your child that this subject matter is uncomfortable and difficult for you to discuss. This may help ease the tension you or your child may feel. Once you begin to share information about sexuality with your child, stay calm and maintain an open mind to what your child may interact with you. Sometimes parents tend to react negatively to what a child may say or do. For instance, if a child is masturbating, it is important to sexual development to recognize this as a normal response to self-exploration and direct the child as to where and when this behavior is appropriate. The above response may assist the child in being more open about his or her sexuality and promote positive feelings about his or her own sexual development. Remember that your reaction will set the stage of how your child will perceive sexuality.

Also, when your child is seeking information on sexuality it is important to be honest with him or her, be direct, do not provide unnecessary information, and use proper terms when describing body parts, or interactions between females and males. Avoid using any silly, rude, or slang names when talking about sexuality issues. For example, a male's genitals should be referred to as penis and testicles, and a woman's genitals as vagina, uterus, and clitoris, etc.

When preparing your child about sexuality it is important that you speak to your child at a level that the child can understand. Making sure that they understand the contents of what you are trying to say and the

vocabulary that you are using, and remember to use proper terms. For example, giving a 5-year old child information on sex from an adult book may not be as understandable as reading them a book from the juvenile section in your library on sexuality. It is important to use age-appropriate material. Also be aware, children of the same age learn differently. What is understandable to one 7-year old may not be to another. It is important that you get a sense of where your child is and how he or she will learn better. Use your judgment, it is the best one concerning your child.

It is hard for many children to express their questions regarding sexuality to their parents. Therefore, it is important that when your child does come to you with questions or concerns that you direct your attention to him or her and listen with sensitivity and respect. It's important that sexuality issues be regarded in a positive sense and not as dirty or bad. When your child develops trust, it will be easier for him or her to approach you about sexuality issues in the future. If your child does not begin asking you questions about sexuality, or demonstrate overt sexual expressions around five to seven years of age it is important that you promote discussion by bringing up the topic yourself. It is important to understand that sexuality is a part of your child's identity and uniqueness, and it should be encouraged and praised, along with the child's emotional and religious development.

Providing a meaningful sex education is one of the most important things that parents can do for their children. It will influence the sexual roles that they choose, the way that they conduct their relationships, and the way that they think and feel about themselves.⁴ Most

young people look to their parents as their most important source of information about sexuality.⁵ Others may also assist in this process, therefore, it is an important aspect of a parent's role to identify those other resources. We are all too familiar with the consequences when the source of information comes from peers at school (e.g., inconsistent information).

The following questions have been designed to prepare you in developing your child's plan. They will help you think about your roles and what you expect will be the outcomes of these roles. Please take some time and answer these questions.

Observations About Myself in Various Roles

In my role as a sex educator:

1. Who else could assist me in understanding my child's needs?

2. Who else can assist me in teaching my child?

3. Do I have the materials and methods that I need?

4. How would I find them?

In my role as a confidant:

1. How comfortable am I in dealing with the range of issues in human sexuality?

2. What issues am I uncomfortable with?

In my role as a role model:

1. How do I respond as a primary source of affection for my child? (emotional, physical, and verbal)

2. How do I relate to other family members and others that I know?

3. How do I demonstrate my own sexuality?

In my role as a value setter:

1. What are our family values around sexuality, both in the home, and in the community?

2. What is the family's expectation for my son or daughter concerning sexuality as an adult? Will they get married? Will they have a significant other?

In my role as a protector:

1. What are my concerns about my child? Now and in the future?

2. Is my child at risk for sexual abuse?
Sexually transmitted diseases? Physical
and emotional disappointments?

An array of roles, choices, and challenges has been discussed. In summary, it is important to recognize the following.⁶

- ◆ that your child is a sexual being with sexual needs and desires
- ◆ the need to encourage appropriate social interactions
- ◆ the need to be supportive of your child's right to sexually express him- or herself, and
- ◆ the need to openly discuss sexuality and your child's feelings about it

Obviously, the most important person in the plan is the child, and his or her preferences, as well as the parents' preferences.

Sex Education: What is it? How to do it?

Sex education is the process that supports your child's plan for healthy sexual development. This chapter defines sexuality and sex education. In addition, it discusses the components and steps necessary to carry out your overall plan.

What is Sexuality and Sex Education?

According to the Sex Information and Education Council of the U.S. (SIECUS),

*human sexuality encompasses the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. It deals with the anatomy, physiology, and bio-chemistry of the sexual response system; with roles, identity, and personality; with individual thoughts, feelings, behaviors, and relationships. It addresses ethical, spiritual, and moral concerns, and group and cultural variations.*⁷

Sex education addresses information concerning the basic facts of life, reproduction, and sexual intercourse as well as more in-depth biological, sociocultural, psychological, and spiritual areas of sexuality.⁸

How do you Begin a Sex Education Program?

The best way to begin a sex education program is to have developed an overall plan for your child. The

format to implement your plan is outlined in Chapter 5.

The following are sequential components of a sex education program:

1. Assess the needs of your child, in terms of skills, knowledge, and environmental challenges
2. Define goals
3. Find resources:
 - a. materials and curriculums
 - b. supportive individuals
4. Develop teaching strategies and assigning responsibilities
5. Implement and evaluate your goals

Assessing the Need

Assessing where your child is in his or her sexual development requires a review of awareness of sexual behavior, knowledge about sexuality, and skills in decision making. It may also involve reviewing the expectations of others in terms of your child's current behavior. An example of this would be, if your child is 15 and runs up and hugs everyone, including people he does not know, this is an important piece of information that you would want to include in your general assessment. Assessment may be accomplished by comparing the expectations of other people in specific environments to your child's behavior in that environment. In this case, information is gathered by talking to teachers, ministers, or friends and family members. It can also be accomplished by simply observing your child in the context of his or her sexual

awareness or responses. This process of checking expectations for appropriate behaviors with others in various environments allows for an informal or unstructured assessment process.

On the other hand, formal or structured assessment procedures may be used to determine your child's knowledge, skills, and ability to determine appropriate and inappropriate sexual behaviors. These assessment tools are most often found with some type of standardized sex education curriculum, such as Winifred Kempton's *Socialization and Sexuality: A Comprehensive Training Guide*. Formalized assessment can also be accomplished by reviewing age appropriate expectations. Normal child development includes a considerable amount of exploration and inquiry. The level at which your child is performing will be fairly evident to you in comparison to others at his or her age. In the following table provided by SIECUS⁹, general expectations for age appropriate information and behaviors are reviewed.

Table 1

What to teach your Child About Sexuality: Age Appropriate Information and Behaviors	
Infants and toddlers (0-2 years)	Naming parts of their body; reacting calmly when they touch their genitals; hold, hug, and talk to them, and respond to their needs
Preschool children (3-4 years)	Simple explanations as to where babies come from; how to bathe, wash their hands, brush their teeth, eat good foods, and nap; need for privacy; create an atmosphere where child feels comfortable in asking about their bodies, health, and sexuality
Young children (5-8 years)	Interested in birth, families, and death; discuss fears about sex and AIDS; discuss bodies and reproduction; give concrete examples from their lives
Preteens (9-12 years)	Changes in puberty; dating, early sexual experiences, and trying drugs; social and peer pressures; sexual intercourse, homosexuality, and oral, anal, and vaginal sex; consequences of sex (e.g. pregnancy and sexually transmitted diseases (STD's)), and prevention of pregnancy and STD's (e.g. contraceptives and condoms)
Teens (13-19 years)	Share family values about sexual behavior; best ways to prevent STD's or pregnancy; make sure your children can protect themselves; talk about the full range of pleasurable sexual behaviors; talk about kissing, hand holding, caressing, masturbation, and other sexual behaviors that do not involve penetration; social pressures; condom and contraceptive use; alcohol and drugs

In considering children with a developmental disability, limitations in cognitive functioning or physical development may or may not be a challenge to the length of time that it takes for them to understand appropriate concepts.

It may also be important that other planning procedures for your child, such as Individual Education Plans (IEP'S), Individual Habilitation Plan's (IHP's), or Person Centered Plan's (PCP'S), such as Personal Futures Plans, be used in order to offer additional useful information. Whatever assessment procedures you use, formal or informal, be sure to include the identification of your child's gifts, strengths, and capabilities, as well as deficits. The important thing to remember about assessment is that it is an ongoing process because the child is continually growing, developing, and changing. A great deal of information can be obtained just as you live with your child on a day to day basis and experience different aspects of his or her personality.

Defining Goals

Goals are simply the end point or level of performance that you hope your child will accomplish in terms of awareness, knowledge, or skills. Jerome Brunner, a well-known educator, once said you can teach anything to anybody if you break it down into small sequential achievable steps. Short-term goals are the steps toward a long-term goal. For example, to have an understanding of reproduction there must be some basic awareness of body parts.

For purposes of your plan, the best way to define a goal is that it emerges from a need. Identify some needs that your child has, set some goals based on these needs,

and other goals will be evident over time. For example, if your daughter says “I want a boyfriend”, this can be a good goal to jointly work on. As you work on this goal, you may find out that all she wants is someone to go with to the movies or out to dinner. The final point about goals is that once you set them you find out a great deal about additional needs as well as the ultimate goal that you and your child desire.

Finding Resources

Finding resources relates to two basic questions: 1) what materials or curriculums do I need, and 2) who can I get to help me? (In terms of other responsible individuals).

Finding supportive materials. There are many excellent supportive teaching materials and curricula focusing on disabilities and sex education. These materials are quite descriptive, not only in content but give good examples on how to use a teaching strategy such as role-playing. It is also important to note that additional goals for your child may be identified in reviewing these materials and curricula. A list of useful materials and curricula may be found in the “Additional Resources” section of this guide. Targeted materials may be requested from the Metropolitan Organization to Counter Sexual Assault Developmental Disabilities Resource Center on Sexuality or the Missouri Developmental Disabilities Resource Center (see Additional Resources section for locations). Additional materials, such as books or videos, can also be obtained from Planned Parenthood, or at a library.

Finding supportive responsible individuals. So far we have discussed your child's needs, defined goals, and identified supporting materials. The question now remains, who will carry out the assignment of providing this information to your child?

Obviously, the most important persons are the parents and the child. However, the significance of parental involvement relates to the design and management of an overall plan. Parents may be more or less involved in actual teaching strategies with, for example, specific curriculum. Teaching strategies in the home should involve parents directly, or with their oversight of others. Teaching strategies in school with particular curriculum should involve parental awareness.

There are also others that can assist in this process, from family members, such as grandparents, aunts and uncles, or brothers and sisters, to close personal friends of the family, to professionals who work with your child. The most significant person, in this case, may be a teacher who is prepared to do sex education and to individualize some materials according to your plan. Very often schools and individual teachers are quite receptive and may see it as one of their responsibilities to teach sex education. If so, it is essential that the school or teachers efforts be coordinated with that of the parents overall plan.

The most important consideration in assigning individuals to carry out portions of the plan should be their willingness, level of comfort, and competence in addressing particular goals. It is at this point that parents can nurture investment of many individuals in their child's current and future development.

Developing Teaching Strategies and Assigning Responsibilities

Teaching strategies are the specific response that you will make in your plan to a defined goal. Teaching strategies could be structured or unstructured. Structured strategies include role-playing, group discussions or classes, and individualized one on one teaching with a particular set of materials that are designed to increase awareness, knowledge, or skills. For example, if you want to address your child's awareness of body parts, a structured response would be teaching a particular curriculum (e.g., Winifred Kempton's *Sex Education*, 1988) either in a group setting, such as a class, or one on one.

Unstructured strategies typically focus on a particular goal and use an event that occurs in everyday life as a means to attaining that goal. For example, an unstructured response might be the identification of a teachable moment when you are watching television.

Teachable moments arise when the opportunity for sharing information on sexuality comes naturally, out of your day to day activities. For instance, you may be watching a movie on television and the actors are sending some type of message concerning sexuality. At this time it would be appropriate to discuss with your child what your values are around the issue in the movie, and ask your child what he or she feels. Such teachable moments can also arise when reading a book, acting affectionate toward your spouse or other kids, listening to music, when a mother is pregnant, or when you become aware that your child is looking at or touching him- or herself in private areas. Of course, these moments will come on

their own when the child comes up to you point blank and asks for information by him- or herself.

Implementing the Program and Evaluating your Goals

Parents are often concerned about when is the right or wrong time to start sex education with their child. There is no right or wrong time. Sex education is provided to all children, in one way or another, from the time they are born. However, the earlier you start with more specific education the better informed your child will become regarding his or her sexuality and prevention of sexual abuse.

Most importantly, there is no wrong or right time to start, or no wrong or right plan. The way to implement a plan is to begin it, see what works, see what doesn't work, see what's good for you, for others, and for your child. Implementing a plan is a process of learning and growing together. There will be mistakes, as well as successes.

Evaluation of a sex education program can be as simple as what is working and what is not. The important aspect to measuring success of your goals is to look at where your child started and assess where he or she is at after a certain point in time. This appraisal may take place in the context of a particular curriculum, or by asking a person responsible for a particular goal as to their assessment, or by getting all those involved in the plan together at a particular point, say one year after your plan has been developed, and reviewing outcomes. The child should be involved in this process, it should be a celebration of accomplishments and a revision of

strategies and goals. See Appendix A for a sample plan that incorporates each of the preceding components. In summary, this chapter has provided an approach to conducting sex education through the overall format of a plan.



A Basic Approach to Sexual Abuse Prevention

The purpose of this chapter is to review basic information concerning sexual abuse prevention that you will need in developing your total plan. Sexual abuse includes a range of sexual activities that are forced upon a person. People with special needs are often unable to choose to stop abuse due to a lack of understanding of what is happening, pressure to comply out of fear, or the need to be accepted by the abuser.¹⁰ One of the main reasons for providing sex education to your child is that it can help prevent sexual abuse of your child. Many are unaware of the importance of sex education in preventing sexual abuse. The more a child knows about his or her own sexuality, good and bad touch, appropriate and inappropriate behavior the greater chance for them to protect themselves from a possible encounter with sexual abuse.

There are various misbeliefs regarding sexual abuse of individuals with special needs. Many believe that individuals with special needs are not vulnerable to sexual assault because:¹¹

- ◆ people feel sorry for or find them undesirable, therefore they will not hurt them
- ◆ they live in protected environments, and are not exposed to dangerous situations, or
- ◆ that they are less vulnerable because they are not sexually active.

On the contrary, individuals with special needs are more vulnerable to sexual assault because:

- ◆ they may have physical as well as cognitive disabilities which make them an “easier victim”¹²
- ◆ they lack knowledge concerning anatomy, intercourse, and other sexual activities, reproduction and sexually transmitted disease
- ◆ they lack information about sexual abuse
- ◆ they are socialized to be compliant, passive, and often with a strong desire to please, and
- ◆ they do not enjoy the same rights, privileges, and opportunities for privacy and healthy sexual relationships that most adults do.¹³

According to the California Department of Developmental Services (1996) 50-90% of individuals with developmental disabilities will be sexually abused during their lifetime. In at least 90% of sexual abuse cases toward individuals with developmental disabilities the perpetrator will be know to them.¹⁴

Children with special needs show an inability to defend themselves, report abuse, and to determine what is inappropriate physical or sexual contact, which puts them at greater risk for sexual abuse.¹⁵ This justifies the need to teach your child appropriate and inappropriate touch and behavior, and when and how to say “no”. The following are some considerations your child should be

aware of in developing his or her plan that you can discuss with them.¹⁶

- ◆ You have the right to like touching one person and not another
- ◆ You have the right to like some types of touching and not others
- ◆ You have the right to change your mind
- ◆ You have the right to not have a reason to choose not to touch or be touched, and an explanation is not necessary
- ◆ No one has the right to push or coerce you into touching
- ◆ No one has the right to threaten you into touching
- ◆ No one has the right to bargain for touch
- ◆ No one has the right to put you down for saying “no”

It is important to inform your child that if he or she feels uncomfortable with how someone is interacting with him or her to tell someone immediately, this can alleviate any further discomfort or fear for your child.

There are various materials and curriculums that can assist you in educating your child on appropriate and inappropriate behavior. One curriculum is the CIRCLES Program. In CIRCLES, individuals are taught to discriminate between different degrees of intimacy and how to adapt their behaviors according to where a person falls within their circle. This program teaches them relationship formation and maintenance according to social norms.¹⁷ CIRCLES assists individuals with special needs in managing their personal responsibility and

social integration. This program promotes the appreciation of diversity and the development of personal values, two components that are crucial to the success of decision making and mutual respect. Additional curriculums and materials associated with sexual abuse prevention can be found in the “Additional Resources” section of this guide.

In summary, the importance of sexual abuse prevention for persons with special needs has been highlighted. Prevention of abuse may be hard to understand. However, being prepared to deal with specific events is not so hard to understand, and preparing your child deal with such events is a goal toward sexual abuse prevention and your child’s plan.



***Developing a Sex Education Plan
for Your Child***

The entire focus of this book has been around the concept of developing a plan for your child's sexual development. According to Robert Perske, a parent of a child with special needs and widely recognized writer in the field of developmental disabilities, healthy sexual development comes from...

*being fed and held close in a loving
mother's arms*
*being tickled and bounced on a father's
knees*
*being hugged and shoved around by
brothers and sisters*
*giving up body wastes at the right time and
in the right place*
*becoming curious about all parts of one's
own body*
*running, playing, and wrestling with
friends in the neighborhood*
girls making fun of boys
girls having their hair pulled
boys getting kicks in the shins from girls
having a best pal of the same sex
*finding strange feelings in one's own
genitals and discovering the pleasurable
feelings one's own hands can produce*
daring to go on a date
having a steady

*feeling strange longings for someone of the
opposite sex
feeling guilty for feeling that way
touching
wanting each other
deciding to have intercourse or to keep
distance
discussing the consequences of togeth-
erness
deciding to break up or to stay together
trying to understand what real love is
talking about marriage
making plans
breaking up
making plans
making commitments in a ceremony—or
making agreements about an emotional
partnership without a ceremony.*¹⁸

These observations pointedly reveal why a plan is important. In addition, a plan is important because:

- 1) it represents an actual goal of your expectations as a parent. The outcome of healthy sexual development is one that should be conscious in the mind of any parent.
- 2) it prepares you and your child to respond to both those learning opportunities, as well as “those crises” that life surely brings.
- 3) it recognizes that as needs evolve over a lifetime, the plan itself must evolve.

- 4) just as it raises your consciousness, as well as your child's, it becomes part of your lifestyle, in the healthiest sense.
- 5) it is something you are doing something about, not just worrying about. So, in the long run your mind may be more at ease.

The rest of this chapter is designed to help you outline your plan. You have already filled out a number of questions that will help you fill in these forms. A sample plan is included in Appendix A to assist you in completing your child's plan. Your plan has three parts and is included in the next set of pages, preceded by a brief explanation of how to fill out the parts. Fill in the blank forms to the best of your ability. Please keep in mind that this is a working plan, it can be changed at any time, and needs, goals, resources, strategies, and evaluation procedures can be added or deleted.



Part I

Assessing the Need(s) and Defining the Goal(s)

The basic process of assessing the needs is described in Chapter 3. To complete this form, the following questions may assist you:

Observations about My Child

There are several questions you should ask yourself to assess the need for sex education of your child.

1. Does my child know his body parts?

2. How does my child express his or her sexual behavior to self and to others?

3. What are appropriate and inappropriate behaviors that my child engages in?

4. Is my child at risk for abuse? Why or why not?

The basic process is to make observations, define needs, and state goals.

Plan for Healthy Sexual Development

Part 1

Assessing the Need and Defining the Goal

Observation:

Need:

Goal:



Part II

Finding Resources

We have provided space for three goals. If there are additional goals that you have for your child feel free to duplicate this form. In Part II, fill out the goals that you decided on in Part I and then decide on who can assist you with each of those goals and what materials or curricula would be helpful in reaching those goals. Appendix B lists various curricula and materials that can be found at MOCSA's Resource Center on Sexuality (<http://safety-first.org>), Planned Parenthood, or the Missouri Developmental Disabilities Resource Center that may assist you with your goals.

Part II
Finding Resources

Goal 1:

Who can help:

Curriculum(s)/Material(s):

Goal 2:

Who can help:

Curriculum(s)/Material(s):

Part II
Finding Resources
(Continued)

Goal 3:

Who can help:

Curriculum(s)/Material(s):

Part III

Strategies, Responsibilities, and Evaluating Goals

In Part III, you will develop strategies and assign responsibilities for each of your child's goals, and evaluate how well the goals that you and your child have set are being met. When developing your strategies, think about who you want to be responsible in implementing what curricula or materials for each specific goal. When evaluating goals, decide when you would like to evaluate each of the goals, and who's input is useful in evaluating whether or not the goal you have has been satisfied. Keep in mind that not all goals will be attained in the period of time you may set. You may need to re-evaluate certain goals, re-assign individuals to different responsibilities, and figure out different strategies if the current ones are not working.

Part III
Strategies, Responsibilities, and Evaluating Goals

Goal 1:

Strategy:

Evaluation:

Goal 2:

Strategy:

Evaluation:

Goal 3:

Strategy:

Evaluation:

No matter your age, sexuality is a part of your life. You begin to feel and establish your sexuality from the second you are born and it lasts throughout your lifetime. Infants and young children begin by finding pleasure in bodily sensations and exploration. Later, adolescents begin to go through puberty and become interested in relationships. As an adult, you establish many personal and close relationships and begin to think about marriage and family.

Going through a positive life long process with sexuality is enhanced by how your parents and family approached or discussed the issues concerning sexuality with you. What a parent may say to, or how a parent might act toward, a child concerning sexuality issues will model and instill values in the child that he or she will carry with him- or herself for the rest of his or her life. That's why it is important as parents to discuss this issue carefully and calmly with your child. Always provide information you are sure is correct and make sure to listen to your child. It is important not to laugh at or embarrass your child when he or she discusses sexuality with you.

Hopefully this book has provided guidance to you in developing a plan on how to prepare your child on sexuality and sexual abuse prevention. As well as providing an important basis for your child's overall development, the process of developing your child's sense of self and interpersonal relationships will strengthen your relationships and your mutual appreciation of each other as people.

Appendix A

Sample Plan for Healthy Sexual Development

Part I

Assessing the Need and Defining the Goal

Part II

Finding Resources

Part III

Strategies, Responsibilities, and Evaluating Goals

Sample Plan for Healthy Sexual Development

Part 1 **Assessing the Need and Defining the Goal**

Observation:

1. Johnny can't identify his body parts.
2. Johnny lets others touch him anywhere. I'm afraid he will be abused.
3. He kisses everyone on the lips.

Need:

1. Johnny needs to learn his body parts.
2. Johnny needs to understand the difference between appropriate and inappropriate touch to his body, and when to say "no".
3. Johnny needs to understand the difference between appropriate and inappropriate self-expression.

Goal:

1. Teach Johnny his body parts.
 2. Teach and explain to Johnny the difference between appropriate and inappropriate touch of his body by others, and when to say "no".
 3. Teach Johnny the difference between appropriate and inappropriate self-expression towards others.
-

Part II Finding Resources

Goal 1:

Teach Johnny his body parts.

Who can help:

1. Johnny's school teacher, Ms. Adams
2. Johnny's brothers and sisters

Curriculum(s)/Material(s): Basic Sex Education

1. Book by L.K. Brown & M. Brown (1997) called What's the big secret?: Talking about sex with girls and boys. Goes through body parts.
2. Book by Winifred Kempton (1993) called Socialization and Sexuality: A comprehensive training Guide. Section on female and male anatomy.

Goal 2:

Teach and explain to Johnny the difference between appropriate and inappropriate touch of his body by others, and when to say "no".

Who can help:

1. Johnny's school teacher
2. Individuals from MOCSA

Curriculum(s)/Material(s): Sexual Abuse Program

1. CIRCLES program. Can be borrowed from MOCSA.

Goal 3:

Teach Johnny appropriate and inappropriate self-expression towards others, and about germs.

Who can help:

1. Johnny's mom and dad, brothers and sisters.

Curriculum(s)/Material(s): On Sexual Expressions

1. None, parents own values.
-

Part III

Strategies, Responsibilities, and Evaluating Goals

Goal 1:

Teach Johnny his body parts.

Strategy:

1. Johnny's brothers and sisters will read him the book called *What's the big secret?: Talking about sex with girls and boys*, two to three times a week
2. Ms. Adams will complete the Kempton curriculum with Johnny at school.

Evaluation:

1. After Johnny's brothers and sisters have read the book to him for two months, they will test him, informally on the difference between the body parts that he knew prior to the reading of the book and what he will know in two months.
2. Johnny's teacher will use a pre-assessment to measure Johnny's knowledge on body parts and basic sex education, and a post-assessment one year later to see if he has learned any additional information.

Goal 2:

Teach and explain to Johnny the difference between appropriate and inappropriate touch of his body by others, and when to say "no".

Strategy:

1. When Johnny's teacher sees that Johnny is letting anyone touch his body she will stop and explain to Johnny the difference between appropriate and inappropriate touch by others, and that when someone is touching him and he doesn't like it he can say "no".
 2. MOCSA staff person will go through and explain to Johnny and his family the CIRCLES program or MOCSA will loan the curriculum for the family to use.
-

Evaluation:

1. Johnny's teacher will record how many times a week she has to stop and explain to Johnny about appropriate and inappropriate behavior of others on his body and when to say "no". After six months, the teacher will meet with the parents to discern if there has been a decrease in the amount of times the teacher had to explain to Johnny the above, from the beginning of the year to the six month mark.
2. After explaining and practicing the CIRCLES program there will be an assessment at six months to see if Johnny has grasped the concept, and through observation of family and friends, if he is using the concept in his life dealings with other individuals.

Goal 3:

Teach Johnny appropriate and inappropriate self-expression towards others, and about germs.

Strategy:

1. Johnny's parents and siblings will model for him appropriate self-expression.
2. Johnny's parents and siblings will role-play situations and proper expressions for those situations.

Evaluation:

1. Johnny's parents and siblings will observe, over a two month period, whether or not modeling and/or role-playing made a difference in how he interacts with other individuals by observing Johnny while interacting with others in various situations.

Appendix B

Additional Resources

Books
Curricula
Videos
Organizations.

Additional Resources

Books

Cowardin, N, Downer, A., & Stanfield, J. (1990). LifeFacts 2: Sexual abuse prevention, essential information about life...for persons with special needs. Santa Barbara, CA: James Stanfield & Company, Inc.

Girard, L. W. (1984). My body is private. Niles, IL: Albert, Whitman, & Company.

Gordon, S. (1991). Girls are girls and boys are boys: So what's the difference?. Buffalo, NY: Prometheus Books.

Gordon, S. (1992). Facts about sex: For today's youth. Amherst, NY: Prometheus Books.

Gordon, S., & Gordon, J. (1992). A better safe than sorry book: A family guide for sexual assault prevention. Buffalo, NY: Prometheus Books.

Gordon, S., & Gordon, J. (1992). Did the sun shine before you were born?: A sex education primer. Buffalo, NY: Prometheus Books.

Herrerias, C. (1993). Parent talk: A parent's guide to child sexual abuse prevention. Charlotte, NC: KIDSRIGHTS.

Hingsburger, D. (1990). Contact: Sexuality and people with developmental disabilities. Mountville, PA: VIDA Publishing.

Hingsburger, D. (1993). Openers: Parents ask questions about sexuality and children with developmental disabilities. Vancouver, British Columbia, CANADA: Family Support Institute Press.

MacFarlane, K., & Cunningham, C. (1996). Steps to healthy touching: A treatment workbook for kids who have problems with sexually inappropriate behavior. Charlotte, NC: KIDSRIGHTS.

Meyer, L. H., Park, H.S., Grenot-Scheyer, M., Schwartz, I. S., & Harry, B. (1998). Making friends: The influences of culture and development. Baltimore, MD: Paul H. Brookes Publishing Co.

Schoen, M., & Quay, M. J. (1990). Bellybuttons are navels. Buffalo, NY: Prometheus Books.

Sheffield, M. (1991). Where do babies come from?. New York: Alfred A. Knopf.

Siegel, P. C. (1991). Changes in you: A beautifully illustrated, simply worded explanation of the changes of puberty for girls (or -for boys). Richmond, VA: Family Life Education Associates.

Stang, L., & Miner, K. R. (1994). Sexuality: Health facts. Santa Cruz, CA: ETR Associates.

Stanfield, J., & Cowardin, N. (1992). LifeFacts: Sexuality, essential information about life...for persons with special needs. Santa Barbara, CA: James Stanfield & Company, Inc.

Curricula

Burton, L. (1994). Teach-A-Bodies: Color-Me-Real Paper Dolls. Fort Worth, TX: Teach A Bodies.

Champagne, M. P., Walker-Hirsch, L., & Stanfield, J. (1993). CIRCLES: Intimacy & relationships. Santa Barbara, CA: James Stanfield Publishing Company.

Krents, E. J., & Brenner, S. A. (1991). No go tell!: Protection curriculum for young children with special needs. Santa Barbara, CA: James Stanfield Company, Inc.

Plummer, C. A. (1984). Preventing sexual abuse: Activities and strategies for those working with children and adolescents. Curriculum guides for k-6, 7-12, and Special populations. Holmes Beach, FL: Learning Publications, Inc.

Ratner, M, & Chamlin, S. (1987). Straight talk: Sexuality education for parents and kids 4-7. New York, NY: Penguin Books.

Siegel, P. (1991). Changes in you: The curriculum, an introduction to sexual education through an understanding of puberty, for students with special needs, grades 3 through 9. Santa Barbara, CA: James Stanfield Company, Inc.

Strangle, J. (1991). F.L.A.S.H. Family life and sexual health: A curriculum for grades 7-12. Seattle: The County of King.

Videos

Inappropriate: Basic concepts for teaching people with developmental disabilities and mental retardation. (1989). Monaco & Associates, Inc.

Meet the new you—boys (or—girls). Charlotte, NC: KIDSRIGHTS.

The new improved me: Understanding body changes. (1991) Pleasantville, NY: Sunburst Communications.

Person to person: A video program about the sexuality education of persons with developmental disabilities. (1991). Cicero, NY: Program Development Associates.

Sexuality education, Evaluations, and treatment of sexual abuse for people with developmental disabilities (Tape 1, 2, 3, and 4) (12-4-1992). Carolyn Schroeder Workshop.

Speaking of sex...and persons with special needs: A conversation (Part 1). Kempton, W., & Stanfield, J. (1988) James Stanfield & Company. (1988).

Speak up say no. Charlotte, NC: KIDSRIGHTS.

Strong kids, safe kids: A family guide. Paramount Home video(1984).

Where Did I Come From? Gayle, P. (1990).

Organizations

Institute for Human Development
Missouri Developmental Disabilities Resource Center
2220 Holmes, 3rd Floor
Kansas City, MO 64108
(816) 235-1763
1-800-444-0821
www.moddrc.com

Metropolitan Organization to Counter Sexual Assault
(MOCSA)
3217 Broadway, Suite 500
Kansas City, MO 64111-2414
(816) 931-4527
www.safety-first.org

Missouri Planning Council for Developmental
Disabilities

1706 E. Elm
P.O. Box 687
Jefferson City, MO 65102
(573) 751-8611
(800) 500-7878
www.modmh.state.mo.us

National Information Center for Children and Youth with
Disabilities (NICHCY)

P.O. Box 1492
Washington, DC 20013-1492
1-800-695-0285
(202) 884-8200
www.nichcy.org

Sex Information and Education Council of the U.S.
(SIECUS)

130 West 42 Street, Suite 350
New York, NY 10036
(212) 819-9770
www.siecus.org

The Arc National headquarters

PO Box 1047
Arlington, TX 76004
(817) 261-6003
thearc@metronet.com (e-mail)
www.TheArc.org

Footnotes

¹Quoted from *Sexuality and People with Intellectual Disabilities* by Lydia Fegan, Ann Rauch, and Wendy McCarthy, pg. 11, published in 1993 by Paul H. Brookes, Baltimore, Maryland.

²Taken from the paper *Beginnings: A parent/child sexuality program for families with puberty aged children with developmental disabilities* by Terri. Couwenhoven--state community education coordinator, Planned Parenthood of Wisconsin—published in March 1991 by the Wisconsin Council on Developmental Disabilities, Madison, Wisconsin.

³Same as footnote number 2.

⁴Information taken from an audio-cassette called *How to talk to your child about sex*, by A. Ulene, and S. Goldsmith (1988), produced by Feeling Fine Programs, Inc., and Random House, Inc.

⁵According to the Sex Information and Education Council of the U.S. (SIECUS) recent polls show that young people find parents as an important source of sexuality information. Taken from SIECUS' web page article *Who should be teaching children about sexuality?* <http://www.siecus.org/parent/question/ques0001.html>

⁶The following information was taken from *About sexuality and people with disabilities* by L. Channing and Bete Co, Inc. (1985). South Deerfield, MA: Same.

⁷Quote taken by Haffner, 1990, p. 28 by SIECUS and cited in *NICHCY News Digest*, Vol I, Number 3, 1992, pg. 2.

⁸Information taken from *NICHCY News Digest*, Vol I, Number 3, 1992.

⁹Information was adapted from information taken from SIECUS on *Communication Tips for Parents*, <http://www.siecus.org/parent/pare0001.html>, and converted into a table

¹⁰Adapted from article by Leigh Ann Reynolds called *People with mental retardation & sexual abuse* cited in article #101-56 Oct. 1997 by The Arc National Headquarters.

¹¹Following points taken from the paper *Beginnings: A parent/child sexuality program for families with puberty aged children with developmental disabilities* by Terri. Couwenhoven--state community education coordinator, Planned Parenthood of Wisconsin—published in March 1991 by the Wisconsin Council

¹²Palle Rilinger-MOCSA, personal communication

¹³Last four points, same as footnote number 11.

¹⁴Same as footnote number 11.

¹⁵Information taken from the *MONITOR* published by the American Psychological Association in an article titled *Disabled children vulnerable to abuse* by S. Sardella, April 1994.

¹⁶Information taken directly from information provided by MOCSA.

¹⁷Information on the CIRCLES program was taken from the Introduction section of the CIRCLES program guide, which is available at MOCSA.

¹⁸Direct quote taken from *Hope for the families: New directions for parents of persons with retardation or other disabilities*, by Robert and Martha Perske, Nashville, TN: Abingdon Press, 1981, pg. 60.

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Brown, L. K., & Brown, M. (1997). What's the big secret?: Talking about sex with girls and boys. Boston, MA: Little, Brown, and Company.

Channing L. Bete Co, Inc. (1985). About sexuality and people with disabilities. South Deerfield, MA: Same.

Couwenhoven, T. (1991). Beginnings: A parent/child sexuality program for families with puberty aged children with developmental disabilities. Madison, Wisconsin: Wisconsin Council on Developmental Disabilities.

Fegan, L., Rach, A, & McCarthy, W. (1993). Sexuality and People with Intellectual Disabilities (2nd ed.). Baltimore, Maryland: Paul H. Brookes.

Kempton, W. (1988). Sex Education: for persons with disabilities that hinder learning. Haverford, PA: James Stanfield Company, Inc.

Sardella, s. (1994). Disabled children vulnerable to abuse. Monitor, April, 37.

Ulene, A, & Goldsmith, S. (1988). How to talk to your child about sex. Audio: Feeling Fine Programs, Inc. and Random House, Inc.

Westheimer, R. (1993). Dr. Ruth talks to kids: Where you came from, how your body changes, and what sex is all about. New York: Macmillan Publishing Company.

We appreciate your review of this book. Please assist us in evaluating how beneficial this book was for you. The following questions have been designed to appraise the content, format, and usefulness of the book. Your comments will help us improve and revise the book in the future. Please return the following Parent Evaluation to the address indicated on the back of the form.

Thank you,
Christina Karakoussis
Carl F. Calkins
Karen Eggeling

PARENT(S) EVALUATION

Please put a check mark (✓) in the space next to the response that best reflects your position on each of the following questions.

1. Was the book useful in developing a sex education plan for your child?

Yes___ No___

How can the book be more useful?

2. Does the organization of the book make sense to you?

Yes___ No___

If no, how could it be improved?

3. Does the plan make sense to you?

Yes___ No___

If no, how could it be improved?

4. Did your awareness of sexuality issues change as a result of reading and working with this book?

Yes___ No___

If yes, in what ways?

5. Would you recommend this book to other parents?

Yes___ No___

Why?

Additional comments

Please return this evaluation to:

UMKC Institute for Human Developmenta, UCEDD

Attention: Christina I. Mitef

2220 Holmes, 3rd Floor

Kansas City, MO 64108-2676

Fax: 816 235-1762