# Sexuality and Developmental Disabilities

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Sexuality and Developmental Disabilities

This training manual was revised by the North Dakota Center for Persons with Disabilities to be used by North Dakota community provider agencies participating in the Community Staff Training Project through Minot State University. We encourage the use of this publication for not-for-profit organizations for educational and research purposes. We requests that appropriate acknowledgement be given for use of this publication for any other purpose should be submitted to Minot State University, NDCPD, Community Staff Training Project, Box 131, Minot, ND 58707. We request that appropriate acknowledgment be given.

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Sexuality and Developmental Disabilities

Why teach about sexuality? Unfortunately, in the past many have viewed individuals with developmental disabilities as perpetual "children", even though they were fully grown adults. This misperception is still held by some people. As a result, it's often been assumed that individuals with special needs are without normal sexuality throughout their lifecycle as children, teenagers, and adults. Nothing could be further from the truth! All human beings, regardless of possible handicapping conditions, have their own rate of sexual growth embedded deep within their personalities; this is also linked to self esteem. Most people have a self-concept that is united with their being male or female.

From birth, individuals receive messages about their sexuality. An awareness of sexual identity is present from infancy; each day a person's life experiences add to his or her self-perception as a male or female, as attractive or unattractive, and as valued or unloveable.

Individuals with developmental disabilities are more like other people than they are different, and, by and large, have normal sexuality. It is hard enough for others in our society to learn to use this very beautiful and powerful gift for constructive rather than destructive ends. For a person with any combination of developmental lags, it may be even more difficult.

Staff and interdisciplinary teams seek a course that will incorporate healthy values, self-esteem and sexual responsibility for oneself and for others. This information will prepare teams to assist individuals with disabilities to plan goals and objectives regarding sexuality, and train staff members to take advantage of "teachable moments". Although the stages of development may have been delayed, some impressions may be distorted, and some experiences may have been insulated, nearly all people desire touch, tenderness, and love.

You will notice references to curriculum materials, slides, videos, and games at the end of many of the chapters. These materials are available to all North Dakota educators and service providers from the North Dakota Parent Assistance and Supportive Schools (NDPASS) in Minot. Library items are available for check out at no cost if accessed at the Center. Items can be mailed, but please note there will be a charge for shipping and handling for professionals. Postage costs are $2.50 per book or video. This charge covers the cost of mailing out the item(s) and a large stamped return envelope to mail resources back to the library. We will enclose an invoice with your requested library materials. You may access the library in person at the Arrowhead Center, Minot; or order resources via email, telephone, or mail.

NDPASS/Pathfinder Family Center
1600 2nd Avenue SW #19
Minot ND 58701-3459

PTI: 1-800-245-5840 or 837-7500
NDPASS: 1-888-763-7277 or 837-7510
http://www.pathfinder.minot.com/index2.html

Best wishes in your efforts to gain insights and direction from this module as well as in your efforts to counsel and educate individuals on a day-to-day basis.
UNIT 1: Promoting Healthy Social/Sexual Development

Objectives:

After completing this unit staff members will be able to:

- Describe appropriate instructional guidelines for teaching social/sexual issues with individuals with developmental disabilities.
- Explain the need to assist individuals with developmental disabilities to understand sexuality.

Sexual development is:

Being held close in a mother's arms and being fed.
Being tickled and bounced on a father's knee.
Being hugged and shoved around by brothers and sisters.
Feeling the relief of giving up body wastes at the right time and in the right place.
Having curiosity about all parts of one's body.
Running, playing and wrestling with friends in the neighborhood.
Girls making fun of boys and boys teasing girls.
Having a best friend and always wanting to be with him/her.
Touching ourselves and discovering the exciting feelings one's own hands can produce.
Going on a date.
Having a steady.
Feeling a strange attraction for one another and feeling fearful and guilty because of it.
Touching.
Wanting each other.
Deciding to have intercourse or keep a distance.
Deciding to break up or stay together.
Making plans.
Discussing what real love is.
Living together.
Talking about marriage.
Marriage.
Having kids.
Breaking up.
Divorce.

Robert Perske
In the scheme of life, there are not many things more important than relationships. Staff members play an important role assisting people to develop healthy relationships and sexual lives. Support providers do this both formally and informally.

Formal teaching activities, while important, may only be appropriate at certain times. Formal social/sexual education is planned with the individual and his or her team and provided by direct support staff and other team members. Person-centered plans are the individualized strategies for achieving desired outcomes for people.

Informal teaching is provided through daily interactions. Some well-known experts in this area claim that this is the most powerful and important education possible. So, the role of the direct support worker is vital to the psychological and sexual health of the consumer.

The following suggestions are presented to give support workers guidelines for informal interactions and social/sexual education for individuals with developmental disabilities. Guidelines for staff include:

**Be an approachable person.**
- Relate to and accept the person.
- Accept sexuality as a positive force.
- Be able to discuss sexuality with ease and comfort and allow others to communicate freely about sexual matters.
- Have compassion, warmth and trustworthiness.
- Examine your own attitudes about sexuality and separate those from the needs of the person.
- Try not to be judgmental. Open communication can be lost easily in this emotional and sensitive area.

Be ready to supply necessary training at developmental stages. Be knowledgeable yourself and ready to provide information that may be required. Staff members provide important sex education, whether they decide to or not, simply by their behavior and attitudes. Even not discussing it teaches people that there may be something to hide. This can lead to misinformation or guilt.

In addition to providing for other physical and emotional needs of individuals receiving services, staff members are responsible for offering honest, accurate information to encourage learning and self-esteem, foster communication, and teach people how to avoid difficult or dangerous situations. Winnifred Kempton, an internationally known expert on sex education for individuals with disabilities, offers these points to consider with regard to typical social/sexual development. Kempton’s guidelines can be applied for social/sexual instruction for people with cognitive disabilities of any age.

- **Young children should be taught body parts, including penis and vagina.** They should learn, as they get older, how babies are made and that not all people choose to marry or to have children.

- **Help children understand the changes that occur during puberty.**
Before a young girl begins to menstruate or a boy has his first wet dream, the person should be told what to expect. Teaching should be simple and specific, always pairing with praise for maturing.

- **All young adults must be allowed to make choices about their personal sexual values.** Providers should discuss, as objectively as possible, options on decisions such as sex outside of marriage, use of birth control, and the implications of parenting. It is essential that providers understand the right of individuals to make their own choices about such issues, if possible, and that those choices may not be the same ones that the provider or the person’s family would make.

- **Effectively deal with inappropriate sexual behavior as it occurs.** Inappropriate sexual behavior can be generally described as behavior that would include imposing a person's sexual desires on someone who is not willing, sexual contact with a minor, and some public sexual behavior.

- **The discrimination of "public" versus "private" behavior should be taught.** This can be a problem in settings that provide little privacy. Service programs should have specific policies and guidelines for dealing with inappropriate sexual behavior (i.e., masturbating in common areas shared by all residents). The topic of developing and implementing a policy will be addressed fully in a unit to follow.

- **Help individuals to express their feelings positively toward other people.** Special relationships have a chance to develop when we make opportunities available for individuals to be with and to enjoy each other. Learning to express affection, love, and intimacy in positive healthy ways is just as important in a person's training as is personal hygiene or the biological facts of life.

- **Be aware of the sexual rights of individuals.** In order to exercise their legal rights, individuals need to make informed and responsible decisions. In some instances, this requires knowledge of human sexuality. Legal and human rights will be discussed in greater detail in another section of the module.

**Assisting Individuals with Developmental Disabilities to Understand Sexuality**

Important staff responsibilities include helping individuals to understand sexual roles and norms, family relationships, and sexual feelings. Assistance may be needed because of difficulty in learning, physical and social overprotection, and various living situations. Each type of situation requires different knowledge and skills from staff.

a. **Difficulties in Learning.** A person who has difficulty learning may not have access to or understand information in typical sources such as books, magazines, videotapes, or films. They may also need extra help in developing positive feelings about themselves and about their sexuality.
Limited exposure to the community, combined with difficulty in learning, may result in not knowing when or whom to ask for help. In addition, because individuals with developmental disabilities are more vulnerable to sexual exploitation and abuse than other people, there is a special need for education in these areas.

b. **Overprotection.** When people grow up with limited opportunities to learn from one small risk to another, there is also limited opportunity to develop good judgment about their sexuality. Often, well-intentioned families and professionals have overprotected individuals with disabilities from making mistakes concerning their sexuality. Instead of experiencing low-risk mistakes throughout the developmental stages, individuals with developmental disabilities sometimes have to make major decisions and deal with large risks without benefit of prior learning.

As one expert in the field of human awareness and growth says, "It is unrealistic of society to demand responsible sexual behavior from people who have never been taught what constitutes responsibility and irresponsibility in sexual matters."

What Do You Think? Is a person who has been very protected likely to be gullible (easily fooled)?

c. **Segregated Living Situations.** The trend today is for individuals with disabilities to grow up in typical home situations, go to school, and then go to work/training opportunities. Hopefully, they have many opportunities to learn in normal conditions. Unfortunately, however, others have been exposed to very different learning situations. In programs that are removed from the mainstream of society, such as institutions, segregated schools, and other isolated programs there may be limited opportunities to develop typical social/sexual skills. In some situations, atypical, abnormal sexual behaviors and attitudes may be shaped and reinforced. What is acceptable in an isolated setting is not necessarily acceptable in most communities. Appropriate behaviors, social skills, and sexual roles are fostered by community integration and participation.

d. **Group Living Situations.** Let us consider possible difficulties encountered in group-living situations, where privacy may be rare. If you lived there, how would a lack of privacy and individuality affect your self-esteem? How would your sense of self and sexuality be affected if you could rarely be alone by yourself or with another person of your choice?

e. **Supported Living Environments.** People in supported living have yet another set of needs. Some may have roommate difficulties or may be more vulnerable to abuse or exploitation as they are alone for a good part of the time.
Social/Sexual Relationships

An important part of most adults’ lives is their social/sexual relationships. For the vast majority of us, sexual identity is very much a part of our social relationships. Little boys and little girls learn from early childhood how to behave as men and women. They may play with particular toys and imitate the mannerisms and roles of men and women they know. How individuals respond to others and who they think they are is a vital part of orientation to daily life for men and women.

Adults with disabilities experience similar physical, emotional, and identity needs as the rest of the population. Most adolescents and adults with disabilities have social/sexual interests similar to everyone else’s. However, the ability of a person with a disability to form social relationships may be complicated by the attitudes and prejudices of society.

In the area of social/sexual relationships, staff are concerned with how to teach appropriate behavior and how to balance risk and opportunity. Beliefs about what a person should and should not do in the area of social/sexual relationships are very personal. They tend to be closely tied to religious and other social/cultural values.

A relevant concern centers upon the type and severity of an individual's disability. Social/sexual options are usually limited for someone with a profound disability. Individuals with less severe impairments may need information and support in more complex issues of sexuality, marriage, and parenthood. Of course, there's a wide range in between - a broad gray area, so-to-speak. Each person is unique with respect to social/sexual relationships.

Sexuality and Personal Outcomes

The Council on Quality and Leadership in Supports for People with Disabilities (The Council) uses Personal Outcome Measures to accredit agencies that provide services to people with developmental disabilities. The Council defines quality services by the organization’s responsiveness to people receiving support and their attainment of “Personal Outcomes.”

Personal Outcomes are what people expect from the services and supports they receive. Personal Outcomes encompass major expectations that all people have in their lives, yet are individualized to focus on the issues that matter most to each person. There is no standard definition of any outcome that applies to all members of a group of people. In fact, it is unlikely that any two people will define personal outcomes in exactly the same manner. Personal outcomes are
discovered by talking to the person, observing them in their day-to-day interactions and paying attention to cues that tell what is important to the individual and why.

This module focuses on sexuality issues related to supporting individuals with cognitive and other developmental disabilities. However, don’t forget why this training is important. Assisting individuals with learning about and expressing their sexuality is one of the supports that will make it possible for them to achieve their personal outcomes.

“People Have Intimate Relationships.” People with disabilities should have the opportunity to develop close, trusting, and committed relationships. The definition of “intimate relationships” varies from one individual to another depending on the unique characteristics of the person. While some intimate relationships result in physical affection and sexuality, intimacy also includes intellectual, social, emotional, and spiritual aspects. Each person defines the need and the meaning of intimacy in his or her life.

The options for intimate relationship for people with disabilities should match those available to anyone. Rather than creating barriers to close relationships, service agencies should respect and support individual’s who desire intimate relationships. The Council identifies the following roles for service and support agencies who assist people in achieving this outcome:

- Provide assistance for people to learn about relationships
- Assist the person in making choices
- Support people in arranging and accessing opportunities for relationships.

To determine whether or not this outcome is present, The Council suggests using these questions (among others) in conversations with the person:

- Who are you closest to?
- Is there someone with whom you share your personal thoughts or feelings?
- Whom do you trust to talk with about private concerns and feelings?
- Who is there for you when you need to talk?
- With whom do you share your good and bad feelings?
- Is this enough for you?

Staff members who provide support to the person are responsible to know:

- How does the person define “intimacy?”
- Do you know if the person has the type and degree of intimacy desired?
- How do you support the person’s choices for intimate relationships

**Sexuality and Other Personal Outcome Measures.** While the link between sexuality and the Council’s “intimate relationships” personal outcome is quite obvious, provision of sexuality education and supports for expression of one’s sexuality impact several other Personal Outcome Measures including:

- People perform different social roles.
- People have friends.
- People are satisfied with their personal life situations.
- People are connected to natural support networks.
- People are respected.
- People are free from abuse and neglect.
- People have the best possible health.
- People are safe.
- People exercise rights.
- People realize personal goals.
- People have time, space, and opportunity for privacy.

Another Personal Outcome Measure to consider related to sexuality issues is “People decide when to share their personal information.” Many issues related to relationships and sexuality are very private. Some individuals may not want these very confidential issues disclosed at a very public meeting. Some people at the meeting do not have a need to know the person’s desires in this area and, more importantly, the individual has a right to decide with whom to share personal information.

**What do you think?** How do the supports that you provide help individuals receiving services attain their Personal Outcomes related to relationships and sexuality?

**Curriculum Resources and Information Related to This Topic:**

**Videos:**

*Living in the Real World.* Good training for workers from group home settings.

*Problem Solving* with training module competency test. Depicts how staff can assist with different problems that arise between two roommates who share a home in a minimally supervised/supported living setting. Role-play of solutions.

**Websites** with general information on sexuality:

Kaiser Family Foundation site, with general info: [http://www.itsyoursexlife.org/](http://www.itsyoursexlife.org/)

General info on sexuality @ Columbia University’s general health Q&A site: [http://www.goaskalice.columbia.edu/](http://www.goaskalice.columbia.edu/)
Unit 1: Feedback Exercise

1. Consider the following topics for social/sexual instruction. Pick at least three of the topics and identify individuals whom you support who may benefit from informal or formal teaching on this topic. Explain your answers
   - Body parts, including penis and vagina
   - Changes that occur during puberty
   - Birth control and the implications of parenting
   - Discrimination of “public” versus “private” behavior
   - Inappropriate sexual behavior (imposing a person’s sexual desires on someone who is not willing, sexual contact with a minor, public sexual behavior)
   - Expressing affection, love and intimacy
   - Sexual rights
   - Sexually transmitted diseases

2. List at least two suggestions presented in this unit for including social/sexual education in day-to-day interactions with individuals with developmental disabilities?

3. What are five factors that could influence an individual's understanding about sexuality?

4. Describe the role of staff in supporting people to achieve the personal outcome measure, “People Have Intimate Relationships”: 
UNIT 2: Valuing Relationships

Objectives:

After completing this unit staff members will be able to:

- Explain what a social support network is.
- Define the word "relationship".
- Relate the various qualities of a close, positive relationship.
- Identify uses for a relationship map.

A module dealing with the varied issues of sexuality would be incomplete without a unit devoting itself to relationships. Most people go through life with regular contact with others. We are surrounded by family, friends, neighbors, coworkers, as well as strangers met in passing. Relationships are established with all of these people. Many are fleeting, like the woman who smiled at us at the check-out line yesterday. Others are deep and enduring, like the relationships between parents and children and between husbands and wives. The range of relationships people develop is called their social support network. All types and degrees of relationships are included in this network, including short to long term; impersonal to intimate; negative to positive. A strong, social network is just as important to the development of an individual with disabilities as it is to anyone else. Don't devalue, or pass over as unimportant, any element of the network. Even those "nod-on-the-street", "checkout counter" kinds of contact have tremendous potential for providing many of the good things a social support network is supposed to provide. It's a very personal kind of experience. Similar moments are available to every one of us and should be available to every one of the individuals served, as well.

The word "relationship" has a variety of components and implications.

a. A relationship does not necessarily refer only to dating or being married to or living with someone else. A relationship, for the purposes of this module, means any kind of connection (especially a close connection) that one has with someone else.

b. It's not possible to choose all relationships. For example, people don't get to choose their own family or relatives. But many relationships, whether good friendships or a sexual involvement, are chosen.

c. No one relationship can meet all of a person's needs. Different relationships are developed to meet different needs.

d. In close, positive relationships:
   o Both people trust each other.
   o They can be honest with one another and be themselves.
   o The relationship is not a constant drain on either person's energy. Both people in the relationship feel good about themselves.
   o Neither person is in charge all of the time or takes orders all of the time. There's a sharing of responsibility and effort.
   o Even though the people involved generally enjoy each other's company, they don't have to be together all of the time.
In addition to their shared interests, each person has some interests that are different from the other person’s.

- There are more "ups" than "downs" in the relationship. If most feelings are jealousy, resentment, misery, or anger, it's recommended that a person take another look at that relationship to see if it's a healthy one.
- One feels like a whole person whether they're with or apart from the other person. They don't look to the other person to "make them whole."

We treat various relationships in our lives differently and we expect different things from each.

**Relationship Mapping**

Our relationships, or social support network, can be mapped on a continuum or scale. Typical relationships are found on both sides of the arrow. These are listed from left to right in the order of the depth of intimacy (see below). On one side of the continuum, elements of sexual intimacy are detailed, on the other side, elements of emotional intimacy are detailed. This continuum is arranged from least to most intimate with regard to sexual or physical intimacy. However, different people may arrange their continuum of emotional intimacy in a slightly different order, i.e., some may find themselves more emotionally intimate with a parent than a spouse.

<table>
<thead>
<tr>
<th>LESS INTIMATE</th>
<th>Sexual Intimacy</th>
<th>Physical proximity</th>
<th>MORE INTIMATE</th>
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<td>support &amp; help</td>
<td>confide in</td>
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<tr>
<td>Emotional Intimacy</td>
<td>support, sharing, confidences</td>
<td>private jokes</td>
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Using the Continuum

Assessing: Assess a person’s understanding of the difference in relationships. Discover if there is a possible or potential problem or conflict between emotional and physical intimacy. Examples might be a person who is hugging her boss, or a person having an exclusive, sexual relationship
but doesn’t think his partner is being exclusive. This information can be used to identify areas to teach informally or develop a plan to change the circumstances of relationships in one’s life.

**Teaching:** Teach culturally proper physical and emotional distance for self-protection and safety as well as for inclusion and social acceptance. People with cognitive disabilities often struggle with subtle social mores and cues due to their difficulty with discrimination. They often need help knowing the difference between an acquaintance and a friend, or how their interactions with a co-worker and a boss might differ.

**Sustaining/Building Relationships:** Insert names of those involved in one’s life into the continuum. This alerts staff to support the person in sustaining those important relationships. Mapping will also identify the types of relationships that are missing from the person’s life. This might help the team plan for the future.

**Planning:** After mapping relationships, the person can be assisted to identify changes in relationships that he or she would like to make. Perhaps, they might want to add more friends to their lives, find a parent figure if they are missing one, intensify an acquaintance into a friendship, or develop a significant, exclusive sexual relationship. The team will be informed of the need, which will be put into a plan to help the person attain the outcome they desire.

**What Do You Think?** Should every person’s plan include support for the development and maintenance of relationships? Consider other valuable ways to use a relationship map.

**Curriculum Resources and Information Related to This Topic:**

**Curriculum/Game:**

*In My Shoes: FriendMaking.* Staff training board game and exercises, to teach staff about how to assist people with disabilities to develop relationships.

**Videos:**

*Just Friends.* Helps staff learn how to foster long-term relationships. Video looks at three different relationships between students with and without disabilities.

*Circles.* 12 videos (and other materials) trainer may want to preview and plan for sessions with individuals. Teaches one to protect self and physical proximity/boundaries for various relationships. For those who learn via concrete and realistic examples. Intimacy and relationships; helps students to recognize exploitive relationships and develop mutually respectful ones. (2 parts) Part One- Social distance helps students see/experience social and sexual distances; explains the relationship between level of intimacy and ways to touch, talk, trust each other. Students will learn "relationship
boundaries". Specific behaviors (ex: it's okay to hug your mom but not the mailman). Part Two - Relationship building - intimacy levels change as relationships change. The role of mutual choice among individuals - critical concepts for protecting students from exploitation.

*Friendship Series 1.* Distinguishes between acquaintances, strangers and friends; gives 5 descriptors; shows how to interpret body language; demonstrates over-friendly and intrusive behaviors; appropriate places to befriend people. Excellent workbook for staff to use in facilitating discussions, role plays, practice opportunities, etc.

*The Boyfriend/Girlfriend Series 2.* Shows nuances which are often difficult to discriminate, i.e., moving too close too fast; common issues between men and women, abuse, selfishness, love/sex, disagreements, breaking up; 5 rules for having a good relationship. Good for homosexual or heterosexual relationships.

*The Sexuality Series 3.* Visuals about planning for sexual activity; talking about sex and personal preferences and how to work out those disagreements; sexual offenses; rape by known and unknown persons; differences between public and private places; work and group home situations. Good for homosexual or heterosexual relationships.

*Dating: Making Connections.* Dating - where to go, what to say, how to begin relationships, issues covered are unique and fun. Model both successful and troubled relationships. Film Festival Winner.

**CD-ROM**

*Personal Success.* Reinforces hygiene, dressing, and grooming care skills. Fifty-three activities step-by-step. Six topics: personal care for women, personal care for men, personal care for everyone, dressing for success (men or women) and clothing care. Instructors can block out topic areas as needed.

**CD-ROMs Overlay for Intellikey.**

*Community Success.* Prepare for community outings, addresses both social considerations and step-by-step instructions, illustrates both good and bad behavior. 45 activities.
Unit 2: Feedback Exercise 2

1. Explain what a social support network is.

2. Define the word "relationship".

3. Describe the various qualities of a close, positive relationship.

4. Name at least three uses of relationship mapping.
UNIT 3: Objectively Dealing with Sexuality

Objectives:

After completing this unit staff members will be able to:

- Understand and explain the difference between personal values and factual, fair information and socially acceptable behavior.
- Understand and explain personal comfort zones.

This unit addresses a sensitive topic for many people. It deals with a small, yet very important, part of a much larger issue. We must initially rid ourselves of myths and separate them out from truths.

**Myth:** In 1969 a Judge of the Nebraska Supreme Court said:

> It is an established fact that mental deficiency accelerates sexual impulses and any tendencies toward crime to a harmful degree.

**Fact:** Anna Freud, daughter of the founder of psychoanalysis, born 1895 and died 1982 said:

> Sex is something we do.

> Sexuality is something we are.

**What do you think?** What are your thoughts about these 2 statements?

**Personal Value System**

It is important to discover your personal comfort zones through such self-introspection. Take time to identify your personal attitudes and values toward the sexual behavior of others. It is not possible to force anyone, including oneself, to adopt specific beliefs or values. Staff must learn to accept themselves the way they are. The most important aspect of interaction with individuals is staff attitude and level of comfort. If a subject comes up in which the staff person is not comfortable, he or she must refer that issue to another person.

The staff person’s values don't need to be the same as what is taught or counseled. The duty of staff is to share factual information and socially acceptable behaviors, not values. Socially acceptable behaviors are those that would be considered typical of others in the community. Our values are shaped by our what we were taught by our parents, religious beliefs, life experiences, or societal pressure. As a staff member, learning to recognize one's personal value system is an important step toward becoming comfortable and effective when dealing with sexuality issues. If the staff person cannot separate their values from factual information and socially acceptable behaviors that they are expected to teach, he or she shouldn’t
address the issue. It should be referred to someone who can.

Here you will examine your values and comfort zones regarding issues of sexuality. Sexuality is made up of many components: physical, cosmetic, dress, feeling, relationships, self-image, values, touch, etc. Sexual acts are only one part of sexuality.

Most employees will be comfortable with the majority of issues considered a part of human sexuality.

Acceptability Continuum

Using a continuum like the example below, enter the number of the item (from the list that follows) on the line where that issue is comfortable for you.

**Example (See the code which follows):**

<table>
<thead>
<tr>
<th>17</th>
<th>4</th>
<th>2</th>
<th>15</th>
<th>3</th>
<th>20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptable to me</td>
<td>Does not matter to me</td>
<td>Unacceptable to me</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Answer how you feel right now.** Don’t think too hard on each item. Answer quickly. (Use the code above.)

<table>
<thead>
<tr>
<th>Acceptable to me</th>
<th>Does not matter to me</th>
<th>Unacceptable to me</th>
</tr>
</thead>
</table>

1. Technical virginity - "everything but" 11. Extramarital sex
2. Virginity before marriage 12. Promiscuity
3. Sterilization as prevention of pregnancy 13. Sex without love
5. Abortion for myself or partner 15. Tenderness as a condition for sex
6. Homosexuality as a lifestyle 16. Masturbation
7. Bisexuality as a lifestyle 17. Sex with love
8. Pre-marital sex 18. Exhibitionism
10. Interracial sex 20. Use of pornography

Adapted from Morrison & Price (1)

**Discussion:** You may have had difficulty with some items. There may have been conflict for you at times. This is only natural, as many of those issues are controversial. Take masturbation for example. You may have read somewhere that it is a perfectly natural, normal, and healthy thing to do. This is your mind working. But your initial reaction may be that it is unacceptable to you.
This is your basic feeling and value on the subject of masturbation. You face the age-old problem of "head versus gut"; one saying it's healthy, the other saying you feel guilty and uneasy.

**Sexuality Questionnaire**

Quickly react to the statements below. Mark the "Agree" or "Disagree" column according to what you know or feel about each item. If you are undecided after 15 seconds, mark between the columns.

<table>
<thead>
<tr>
<th></th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Individuals with developmental disabilities &quot;act out&quot; sexually like the rest of us.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Parents of individuals with intellectual disabilities discourage adult behavior.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Women with DD want to become pregnant because they see having a baby as proof as being &quot;normal.&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Children born from couples with DD are a social injustice.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Poor self-images among individuals with developmental disabilities are the result of insufficient positive reinforcement.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Marriage without children should be encouraged for adults with developmental disabilities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. It is considered unwise to allow adolescents with DD to spend too much time alone together.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Homosexuality among individuals with disabilities exists because heterosexuality has been discouraged.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Physical attractiveness is as important to individuals with disabilities as it is to us.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Individuals with developmental disabilities should be taught when, where, and how to masturbate.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Developed by Roger Mellott and Cathy Gable, Planned Parenthood of Pittsburgh, 1976. Revised/1977, Rocky Mountain Planned Parenthood Training Center

**Discussion:**

Statement 1: Individuals with developmental disabilities "act out" sexually like the rest of us.

Discussion: If you are not allowed to act out, how would you react to your frustration? Especially, if your ideas are very different from others? Intervention may be necessary if one's behavior is so deviant that trouble with the law or community will result.
Statement 2: Parents of individuals with intellectual disabilities discourage adult behavior. **Discussion:** Remove the words "individuals with intellectual disabilities" from the question. Does it change your interpretation? How do you define "adult" behavior? Is your behavior always "adult"? When you are home and have your privacy, how do you act? If someone could observe your behavior, how would they interpret and react to it? Often the actions of persons with intellectual disabilities are much more closely scrutinized, resulting in less privacy than others. Their behaviors are more likely to be regarded as a symptom of retardation, rather than of the "glass house" in which they may live.

Statement 3: Women with developmental disabilities want to become pregnant because they see having a baby as proof of being "normal." **Discussion:** Remove the words, "with developmental disabilities" again. There tends to be social pressure on all women to bear children.

Statement 4: Children born from couples with developmental disabilities are a social injustice. **Discussion:** The majority of children with developmental disabilities are born to non-disabled parents. In most cases, a couple with disabilities is no more likely to bear a child with disabilities than a "normal" couple, but may need more support services in order to assure environment intellectual disabilities does not result.

Statement 5: Poor self-images among “individuals with developmental disabilities” are the result of insufficient positive reinforcement. **Discussion:** Again remove “individuals with developmental disabilities” and insert "people.” Do you need positive reinforcement? Opportunities for success?

Statement 6: Marriage without children should be encouraged for adults with DD. **Discussion:** Remove "adults with developmental disabilities" and insert socialists, blind, short people, or red heads. Does your reaction change? This is an individual question and should be approached individually.

Statement 7: It is considered unwise to allow adolescents with developmental disabilities to spend too much time alone together. **Discussion:** What is too much? Is adolescence different from childhood or adulthood? Why is it unwise? If the reason is sexual, can education minimize the risk? Or birth control? Is companionship harmful?

Statement 8: Homosexuality among “individuals with developmental disabilities” exists because heterosexuality has been discouraged. **Discussion:** What is homosexuality? It is defined as a predisposition or preference for same sex partners. "Same sex behavior," on the other hand is an adaptation, used when interaction with the opposite sex is restricted. Again remove “individuals with developmental disabilities” and insert "people."
Statement 9: Physical attractiveness is as important to individuals with developmental disabilities as it is to us.

Discussion: Whose concept of physical attractiveness is used? Is something attractive to you attractive to everyone else? Again, a question of values. Should specific training be available so everyone can look, act, and feel their best?

Statement 10: Individuals with DD should be taught when, where, and how to masturbate.

Discussion: Who is comfortable with this? Who should teach it? How is it taught? Masturbation and other acts of self-stimulation issues may be important in your work with individuals with developmental disabilities. Even though most of us know by now that masturbation does not cause acne, blindness or insanity, as was once believed there is still a great deal of anxiety about it.

Interpreting Questions

Sometimes questions asked of staff need to be reinterpreted to determine the individual's real concern. Listen differently and make sure you understand the true inquiry behind the words. Do not always take the question at face value, as there are several possible interpretations for the questions in column 1. In column 2 list some of the hidden questions that an individual may be asking. Try to think of 3 different interpretations for each question.

<table>
<thead>
<tr>
<th>Question</th>
<th>Interpretations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Where do babies come from?</td>
<td>Example: How come I was born this way?</td>
</tr>
<tr>
<td>2. What happens when I play with myself?</td>
<td></td>
</tr>
<tr>
<td>3. Am I attractive?</td>
<td></td>
</tr>
<tr>
<td>4. How can I go about getting sex?</td>
<td></td>
</tr>
<tr>
<td>5. Am I old enough?</td>
<td></td>
</tr>
<tr>
<td>6. How do I make sure I won't have a baby?</td>
<td></td>
</tr>
</tbody>
</table>

From Schulman (10)

A direct support staffer tells of one person who said, “I want to rape a woman.” What would you do if you heard that statement? Responding to the person’s comment with shock or fear could
create a gap or communication barrier between individual and the staff. Instead, the direct support staff wisely asked the person, “What does rape mean to you?” He responded, “Being close to a woman.” This example illustrates the necessity of checking out a person’s perception and meanings of the words they use. If the staff person had responded by correcting the person, he would have lost a good teachable moment, trust may have been destroyed, and the person may have received some bad and harmful information.

You may want to retake some of the exercises from time to time to see if your values change. And take time to reflect upon the origin of your personal values. "Liberal" attitudes are not necessarily "good", and "conservative" attitudes "bad", or vice versa.

**Curriculum Resources and Information Related to This Topic:**

**Websites:**

Susan’s Sex Site: Professional Link is an interesting resource for staff to learn more from articles and interviews with leaders in the area of sexuality and disabilities. [http://www.sexsupport.org](http://www.sexsupport.org)

Sexuality & Disability Bibliography site: [http://www.iidc.indiana.edu/cedir/sexuality.html](http://www.iidc.indiana.edu/cedir/sexuality.html)

Sexual Health Network, good general disability site with a lot of info and advice, use search option for section on DD info: [http://www.sexualhealth.com/](http://www.sexualhealth.com/)
Unit 3: Feedback Exercise

1. Why is it important to explore our own personal values?

2. Name 3 things that can be considered “sexuality”.

3. Why should we carefully consider sexuality questions by people with cognitive disabilities?
UNIT 4: Objectively Dealing with Sexual Behavior

Objectives:

After completing this unit staff members will be able to:

- Separate personal values regarding relationships from professional responsibilities.
- List and justify general societal goals used to shape the development of human growth and awareness policies.
- Explain the sexual rights and responsibilities of individuals receiving supports.

Rights

The sexual rights of individuals receiving services have been addressed on a global, national and state level. In addition many service agencies have their own internal policies regarding this topic. All staff should be familiar with agency policies in this area.

Global.

Article I of the United Declaration of Human Rights proclaims that “The mentally retarded person has the same basic rights as other citizens of the same country and of the same age.”

National


Policy Statement: People with intellectual disabilities and related developmental disabilities1, like all people, have inherent sexual rights and basic human needs. These rights and needs must be affirmed, defended, and respected.

Issue: For years, people with intellectual disabilities and related developmental disabilities have been thought to be asexual, having no need for loving, fulfilling relationships with others. Individual rights to sexuality, which is essential to human health and well-being, have been

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1 "People with intellectual disabilities and related developmental disabilities" refers to our constituency, i.e., those defined by the AAMR classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.
denied. This loss has affected them broadly in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. At the same time, forced participation in sexual activity is an issue for people with cognitive limitations. Because they are considered asexual, our constituents frequently lack access to appropriate sex education in schools and as adults and to training in parenting and child-rearing. Moreover, the general public maintains other out-of-date views of the sexuality of our constituents. Most people have an unfounded fear that parents with intellectual disabilities cannot rear or financially support their children and thus will require more government support, including placement of children in the foster care system.

Position: Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of intellectual disabilities and related developmental disabilities, regardless of severity, does not, in itself, justify loss of rights related to sexuality.

All people have the right within interpersonal relationships to:

- Develop friendships and emotional relationships where they can love and be loved and start and stop the relationships as they choose.
- Dignity and respect.
- Privacy, confidentiality, and freedom of association.

With respect to sexuality, individuals have a right to:

- Sexual expression, reflective of age, social development, cultural values, and social responsibility.
- Information to allow informed decisions, including sex education about such issues as safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases.
- Protection from sexual harassment as well as from physical, sexual, and emotional abuse and sexual relationships with paid staff.

With respect to the potential for having and rearing children, they have the right to:

- Choices related to birth control, including the decision to have and raise children, with supports if necessary; to accept personal responsibility for these decisions; and to have control over their own bodies.
- Have, on an individual basis, access to the proper supports to assist them in rearing their children.
- Choose for themselves whether or not to be sterilized, regardless of the severity of their intellectual disabilities.

States

All states have addressed this most basic right of people. A few of the most obvious rights are:
• The right to make personal choices about sexual values, preferences, and behavior
• The right to be given accurate information about sex education in an understandable way
• The right to sexual expression
• The right to privacy
• The right to have a "significant other" or to marry if the person chooses
• The right to choose parenthood; this also requires the right to be given information about birth control options, and to choose or refuse contraception and/or sterilization
• The right to receive services needed; counseling, legal aid, social, and recreation services with the opposite sex, and so forth.

These rights are considered so basic, that even when someone has been adjudicated incompetent and has a legal guardian assigned in court, he or she still retains the right to a sexual life unless specifically restricted.

Many responsibilities accompany these rights, and they should be included in a complete sex education program. They include:

▪ the responsibility to know and abide by the law and social mores pertaining to sexuality;
▪ protecting oneself and others from sexually transmitted diseases
▪ consideration of pregnancy as a potential outcome of sexual intercourse; and
▪ learning the many tasks and responsibilities of childrearing if that choice is made.

Staff are advised take advantage of the expertise of team members in planning and implementing individualized social/sexual education programs. Issues related to capacity and informed consent need to be in compliance with state law and agency policies.

**Sexual Offense, Sexual Deviation, and Sexual Abuse**

It is important to understand the definition of the following terms:

*Sexual offense* is a sexual behavior prohibited by law.

*Sexual deviation*, a psychological concept, is "...a persistent, predominant, and unconventional sexual interest on the part of an individual either in regard to a particular type of sexual activity or toward a particular type of sexual object or individual." (Sgroi, 1988).

*Sexual abuse* is a form of interpersonal sexual behavior that poses risk or harm to the non-consenting individual.

For example: In some states oral genital sex is prohibited by law, thereby considered a sexual offense. However, when conducted between two consenting individuals, it is not considered sexual abuse. A sexual behavior or activity, such as crossdressing, may not be illegal and thereby
not considered a sexual offense; however, due to the unconventional nature of crossdressing, many professionals classify it as a sexual deviation.

**Separating Personal Values from Professional Behavior**

Staff members need to be aware of the total individual, assuring that physical, emotional, and spiritual needs of the person are being met on an ongoing basis. In all cases, staff members need to be consistent with their approach, following the agency's philosophy and policies.

Dealing with sexual behavior can be challenging. It is the staff member's responsibility to separate personal values and professional responsibilities. We must realize that all people are sexual beings and appropriately and objectively deal with sexual behaviors of individuals receiving services. If a staff person is unable to separate his/her own beliefs/preferences in a given situation, they should ask their supervisor for support and if necessary be removed from the situation.

Here are some basic steps for staff:

- Be objective.
- Consider the situation and the individuals involved.
- Preserve the person’s dignity.
- Respect the person’s rights
- Assist with informed consent for decision-making.
- Teach the appropriate behavior.
- Report the behavior according to agency guidelines.

Now, let's consider each step in more detail.

**Be Objective.** Avoid being judgmental; be objective. Individuals with developmental disabilities are often at a disadvantage in coping with their sexual behavior due to the following:

- They may not know expected social/sexual behaviors.
- They may have a difficult time redirecting their own behavior.
- They may have few or no sexual outlets.

**Consider the Situation.** In each instance, factors such as seriousness of the situation and methods/timing appropriate to the individuals involved need to be considered.

**Preserve the Person's Dignity.** Five actions can be taken to maintain respect for the individual:

- Act calmly. Do not overreact or draw unnecessary negative attention.
- Cover exposed body parts if needed.
- Acknowledge the person's feelings.
- Relieve possible embarrassment to the individual and others by acting professionally and objectively.
• Redirect the person, following agency policies.

Respect the Person’s Rights. All individuals have the right to free association with people of their choice. This includes members of the opposite sex.

Assist the Individual to Make Informed Choices. Informed consent implies three elements:

• Capacity – The ability to express one’s choices. An individual is not assumed to lack capacity simply because he/she has intellectual disabilities or developmental disabilities. The judgment about ability is based on the individual’s previous behavior and the current situation at hand.
• Information – The individual needs adequate information about the proposed choices. This includes, but is not limited to, descriptions of the choice, alternatives, risk of the choice and benefits of the choice.
• Voluntariness – The individual is able to act in the absence of pressure, coercion, duress, threats, inducements, or undue influence by others.

The ability to give consent or need for informed consent must be carefully weighed when the decision involves:

• Risk(s) – Is the situation or procedure dangerous?
• Irreversibility – Can the impact of the choice be reversed?
• Intrusiveness – Does the procedure invade the physical, mental, or social integrity of the individual?

It is usually assumed that a person is competent to make informed choices and provide consent unless it has been established by a court of law that he/she is incompetent. If the court decides that a person is unable to make informed decisions, a guardian is appointed to assist the individual. In these cases, guardians have the legal authority to make certain decisions on behalf of their wards. However, state law mandates that wards be included in decisions affecting them. Furthermore, a guardian cannot consent for some social/sexual decisions (i.e., abortion and sterilization) without court consent.

Teach the Appropriate Behavior. If formal teaching on social/sexual behavior is a part of individual’s Person-Centered plan, follow the plan. If you are unsure of how to implement the plan, ask for assistance. If the plan seems ineffective or inappropriate, document what you observe and follow your agency procedures.

Briefly stated below is a guideline for informal instruction. Staff members should:

• Describe the unacceptable behavior.
• Describe the acceptable behavior.
• Reinforce understanding by getting feedback from the person and by presenting concepts in various ways.
• Acknowledge a person's feelings, perhaps even helping them to recognize and label their feelings.

Report the Behavior. Complete, accurate and objective reporting of sexual behavior, should be strictly confidential. Reporting may promote medical well-being as well as psychological well-being. Good team decision-making is also enhanced.

When describing an incident, here are some factors that staff members may need to consider:

Masturbation:

 o What part of the body was the person stimulating?
 o Was clothing on or off?
 o How was the body part being stimulated?
 o What was being used to stimulate?
 o If someone else was there, what were they doing?
 o Was there observable arousal?
 o How did you intervene?
 o What was the person's reaction?

Sexual behavior with others:

 o Who was involved?
 o Was clothing on or off?
 o What behavior was taking place? (Be specific)
 o What body parts were involved?
 o Was there observable arousal?
 o How did you intervene?
 o What were the individuals' reactions?

Proactive Programming

Agencies who practice “proactive programming” provide support to individuals with disabilities by anticipating and preventing problems. Rather than ignoring sexuality, teams provide individualized social sexual education and supports.

For example, if a man expresses the desire to have a girlfriend, a proactive team would look at how they might assist the person to achieve that goal. They might decide to provide opportunities for the person to meet new people, assist with transportation, teach him how to ask someone to dance, etc. A reactive team would wait until the man did something inappropriate (i.e. tried to kiss one of the staff, a stranger, or a child) before intervening with a plan to correct the inappropriate behavior.
Proactive organizations use the Person-Centered (IPP, IHP, ESP) planning process to promote and enhance development and create support plans to assist individuals to achieve their personal outcomes. Social/sexual personal outcomes are included as a part of the self-assessment and ongoing supports to all individuals with disabilities.

**Policy Implications**

When establishing policies for services to individuals with disabilities, the same general societal goals of typical citizens should be considered. These goals may differ from culture to culture, town to town, family to family, even person to person. Generally, human awareness and growth (or sexuality) policies need to encourage dignity and respect for individuals' sexuality. The factors of privacy, social opportunities, respect for choice and sexuality, and protection of legal rights are considered when establishing an agency policy and services.

- **Privacy:** It is important to recognize the need for private places; rules for respecting each individual's privacy; and possible architectural barriers to privacy.

- **Social Opportunities:** Areas of consideration include sexual integration; opportunities for interaction with the opposite sex; transportation services available, especially evenings and on weekends; social skills training; age-appropriate recreational opportunities; and availability of singles, couples and group activities.

- **Respect for Choices:** Choice of clothing; choice of bedtime; purchase and teaching in use of cosmetics/toiletries as sex-appropriate; choice of roommates; choice of recreational activities; training in sexuality; birth control, avoidance of sexual abuse; relationship issues; are some issues to be considered with regard to making choices. Staff may need training in supporting and encouraging individuals to make choices.

- **Legal Rights:** This area includes specific policies and procedures for responding to inappropriate sexual behavior; guarantee of due process for participation in training programs; information given to staff, parents and individuals about laws, policies and legal rights; and procedures for reporting sexual abuse. Individuals with disabilities need to make informed and responsible decisions in order to exercise their legal rights. In some instances, this involves knowledge of human sexuality. Unless, through due process, an individual is declared incompetent in a court of law, constitutional rights cannot be denied. The legal rights to marry, to procreate, and to raise children are included in these fundamental constitutional rights.

Agencies must consider their policies with regard to sexual expression choices: i.e., if people choose to marry or have children will they still be able to receive services from the same agencies? Will sexual activity be allowed in the residential setting?
To assist in developing specific policies and procedures for dealing with inappropriate sexual behavior consider these guidelines:

- Define appropriate and inappropriate behaviors.
- Establish a procedure to document the behavior and the specific steps taken.
- Provide a positive, proactive.
- Include staff intervention procedures that are both allowed and prohibited.
- Specify circumstances under which specific procedures will be followed.
- Identify who is responsible for the procedures.
- Ensure that due process is used to protect the rights of the individual.

Written policies give staff consistent guidelines to use when responding to sexual behavior. Inconsistent methods in providing supports to people with learning challenges decrease effectiveness of the intervention. If the "mood" of the agency changes or if the range of acceptable behavior changes when the shift changes, progress is less likely. Beyond that, a clear policy provides employees, parents, and consumers with a yardstick to use in helping them decide whether or not the agency is a place they can wholeheartedly support, a place where surprises are minimized.

It's not difficult to find samples of sexuality policies to use as a springboard for agencies who wish to adopt such policies. However, it would be a mistake to simply import another agency's policy intact, uncritically. Getting staff, parents and consumers together to discuss and clarify issues is, perhaps, more important than the document the discussion generates.

The group process can be difficult but powerful. Even though the policy generated may end up looking similar to the sample, when stakeholders have a opportunity to participate in the review process, it becomes a product of the agency. That makes all the difference in the world.
Unit 4: Feedback Exercise

1. Give the five basic steps to aid in good judgment and objectivity, outlined in this unit.

2. Why is it important to make complete, accurate, and objective reports regarding sexual behaviors.

3. The value of an effective policy on sexual behavior is____________.

4. Name 3 rights of people in the area of sexuality.
UNIT 5: Sex Education/Instruction and Dating

Objectives:

After completing this unit staff members will be able to:

- Define and list areas of sex education.
- List the three general headings under which most specific education can be included.
- Understand the importance of individualized instruction.
- Explain the languages of sexuality.
- Identify the primary desire of people.
- Support people in their desire to date and share their life with a partner.

Sex education includes virtually all areas of human relations and self-esteem, including grooming and hygiene, attitudes and values, leisure-time activities, physiological changes, personal feelings and desires, and learning when and how to express those feelings and desires. No matter what an individual's range of abilities are, he or she will experience the touching, caring, and feelings that are part of being alive.

The term sex education usually refers to the provision of information about human sexuality. It also refers to the ongoing process of discovering what it means to be male or female. Education in sexuality can be provided through formal methods such as classroom instruction. However, this type of education can also be quite informal. The goal of the educational process is to develop and enhance a positive attitude toward each person's individual sexuality.

When developing a program of sex education, it is important to identify the person’s needs as perceived and/or expressed by him or her. Staff should support the person to express his or her needs, if possible, and provide direction for education. To prepare people for successful community inclusion, staff members assist individuals with disabilities to understand and express themselves sexually through decision-making in personal, interpersonal, and social situations. Understanding and expressing sexuality requires that the individual have adequate knowledge about his or her physical, emotional, and sexual self, and the ability to express his or her sexuality appropriately. Such understanding is based on self-awareness and the development of self-esteem. The expression of one's sexuality involves respect for others and cultural norms.

While it is true that much education about sexuality for individuals with disabilities is done on an informal basis, it is vital that sex education be carefully planned. Clearly specified goals, support in the environment in which the person will apply their sexual knowledge, and a curriculum that meets the person's needs and provides an active learning experience are fundamental to a successful sex education program.
There are three general headings under which most specific training can be included:

a. Understanding and accepting self (physical and emotional information needs: intra-personal).
b. Building relationships (emotional-social skills: interpersonal).
c. Accepting group mores (social-societal definitions of behavior).

Each person should be given individualized education in human awareness and growth. Individualized goals should neither overwhelm nor shelter people from reaching their potential. Certainly, not all people will be instructed in advanced concepts when they are not emotionally, socially, or intellectually capable of using the information and skills being considered. The following are some basic goals of sex education:

- To provide accurate sex information.
- To teach about the body, generate self-confidence, and heighten self-esteem.
- To provide training in how to identify and avoid sexually exploitative situations.
- To prevent involvement in inappropriate, socially unacceptable, or illegal sexual behavior.
- To help individuals find sexual expression that best fits their abilities and needs.
- To help make it possible to enjoy the company of both sexes by acquiring social skills.
- To offer information about birth control when needed.
- To teach the responsibilities of a sexual person, appropriate sexual behavior and customary social patterns.
- To provide insight into the commitments of friendship, marriage, parenthood, and family for realistic goal-setting.
- To enhance communication about sexuality without unnecessary guilt or embarrassment.

The dangers of not providing individualized sex education include:

- Experiencing doubt and guilt about the body, feelings and normal sexual growth.
- Embarrassment for the person.
- Potential sexual exploitation and abuse.
- Unacceptable social/sexual behavior, perhaps even resulting in legal consequences.
- Possible ridicule and avoidance by society.
- Unplanned pregnancy.
- Sexually transmitted disease.

Staff members should be guided by the specific policies and procedures of the agency and the individual's Person-Centered Plan. Honesty and sincerity are good responses to feelings of anxiety and embarrassment on the part of the staff person or individual. Sometimes, a sense of humor is also a valuable tool in dealing with moments of high anxiety or discomfort. If we approach ongoing sex education with a spirit of teamwork, compassion, understanding, and preparation, our efforts should have a positive impact on the lives of individuals.
**Tips for Interacting**

Never assume that a person’s information about sexual matters is a result of their personal experience. A person’s sexual experience can be arrested at any level: holding hands, kissing, hugging, fondling, nudity, foreplay or intercourse. If someone is discussing intercourse, it doesn’t mean that they have experienced it.

Always consider self-esteem and language capabilities when giving facts: In answer to a question regarding penis size, say 2 – 10” is average, not 5 – 7” erect; when asked when girls begin their periods offer ages between 9 and 16. The broader the range is, the more inclusive your answer.

Take care with humor or cartoon approaches. Some people cannot discriminate the jokes from the reality or catch the subtleties of some humor. Your job as a teacher is to help people learn. Jokes and cartoons will not convey appropriate respect for sexuality and the seriousness of the subject.

Encourage and allow privacy. Only if information of a personal nature will produce a constructive experience should it be disclosed.

Limit the use of charts or anatomical diagrams. Learning to identify and label internal parts is most often useless and confusing. Use actual photos whenever possible. An entire lesson can be built around just one picture.

Don’t give more information than needed. Remember the story of the child who asked where he came from. After his mother explained reproduction, an hour later the child said: “No, what hospital was I born in? James came from St. Mary’s.” Discuss topics at the level that a person can understand and after interpreting the meaning of the question only answer that.

Most interaction on sexual topics can take less than 10 minutes, whether formal or informal. Keep it simple.

**Use of Language**

You may need to ‘talk the talk’ that others use in order to build rapport and trust with them. For some, this may not be easy. If you correct a person’s language too soon you may miss some valuable information they are preparing to share.

There are 3 types of sexual language:

**Street language:** This is often considered to be vulgar and unacceptable. Nevertheless this is a language you may hear.
Common language: Many times this is used in a playful manner. Often nicknames will be used for body parts or activities in a family. Some very original terms are found in this category.

Technical language: This language is one of specific and correct labeling. This would be the proper terminology to use in reporting and you may need to teach these terms.

The following include some terms used during sexuality education.

Penis: Male sexual organ; when aroused it fills with blood and becomes rigid, which is called an Erection. List some other terms you may hear and need to use.

Clitoris: Female sexual organ; when aroused, it too becomes rigid. List some other terms you may hear and need to use.

Orgasm: The climax of sexual excitement; in the male it generally produces semen. List some other terms you may hear and need to use.

Ejaculation: The expelling of semen from the penis. List some other terms you may hear and need to use.

Masturbation: Self-manipulation of body parts to sexually arouse one's self; also referred to as: Sexual Self-Stimulation: Actions done to self which arouse one sexually. List some other terms you may hear and need to use.

Intercourse: Occurs between two people and involves penetrating of the penis into the vagina: Female opening leading to the uterus, or into the Anus: Opening from intestine which expels waste. List some other terms you may hear and need to use.

Homosexual: Attraction to or relation with a member of one's own sex, male-to-male, female-to-female. List some other terms you may hear and need to use.

Heterosexual: Sexual feeling or relations with a person of the opposite sex. List some other terms you may hear and need to use.

Besides intercourse, sexual arousal through bodily contact usually involves touching of self or others in areas of the body associated with sex, such as: Breasts, Anal Area: The area around the anus, or the Genital Area: The area around the penis of a man, or the vagina and clitoris of a woman. It also could involve Oral Manipulation: Using the mouth to fondle a body part. List some other terms you may hear and need to use.

What do you think? How did you feel writing these words? Would you be uncomfortable using them or hearing them from others? A person who is squeamish about street talk will find it almost impossible to establish an open and candid opportunity for sex education.
Creating Outcomes

Formal sexual education is developed through the person-centered planning process. The team identifies outcomes and those responsible for assisting with meeting the goal. The team determines the knowledge, skills and the level of intervention needed. Some plans may require a certified sex educator or a therapist, but most training and supports will be properly assigned to direct support staff. There are numerous curriculum materials to assist with this process.

Assessment. As with any other attempt to create outcomes in an individual’s life, the first step is to assess the current situation, compare it to the desired outcome and fill the gap between the two, moving toward the wanted result. This should be done with as much involvement as possible from the person. There are so many facets to socio-sexual life that no one type of assessment could suffice. Some options include:

- Commercially available tools to assess different aspects of knowledge.
- Self-assessments developed internally, like relationship mapping (see Unit 2).
- Informal observations and interactions can inform the team of a need for understanding of certain concepts, behaviors, or facts.

For example, when staff observed Richard using sexual slang or street language, his team decided to implement a plan to teach him correct terminology. In another situation, a staff person reported observing James become very agitated after bouncing on the floor face down with an erection. The team recognized his behavior as a sign that he wanted to learn how to masturbate to completion.

Planning. We know that we can create outcomes for people in many ways. We start with the end in mind and create steps or analyze the tasks involved in getting from point A (where we start), to point B (where we want to be). But for each person those steps will be different depending upon their current abilities and knowledge. If the teams for two different people decide their plan should contain the same goal of adding two friends to each person’s life, the steps to reach the goal could be entirely different for each person.

For example: The assessment for John indicates that he has many very appropriate social skills, but his lifestyle and work environment do not provide opportunities to meet people. The assessment for Mary indicates that she has few appropriate social skills, but is around people often and in many different environments. The steps to help John and Mary attain their goals would be very different.

**What do you think?** List 8 steps you would take to add a friend to your own life. How would the steps differ if you were helping to create this outcome for a person with a disability?
Your Important Role

Most people want to have a significant other, boyfriend/girlfriend, in their life, but most people with disabilities don’t have the opportunity to share their life with a partner.

- How might the team assist in that?
- How should direct support staff assist with that?
- What kind of opportunities or environments would the person need to have available?
- Where could the person go to meet people?
- What kind of skills (i.e., communication, grooming, social skills) would they need to have? Or what would they need to know?

We know how to teach people just about anything. Why don’t we teach them how to ask for a date, or how to ask someone to dance? Keep in mind that this type of outcome really isn’t that different from any other. For instance, a person who states that he wants to become an astronomer but doesn’t have the cognitive ability required for that profession, can be assisted to join the local star-watcher’s club. We don’t ignore the desire. We help him meet his needs as best we can, at a level appropriate to his abilities. The same holds true in the area of sexuality. It is easy to discount one’s relationship desires if the person identifies that they want their significant other to be a famous movie star. However, we can help a person make many connections with people who may be interested and who are eligible.

When asked, the primary desire of people, any person, is to have significant relationships in life with whom to share their love, dreams and laughter. You can play a key role in helping to make that happen for people with disabilities.

Curriculum Resources and Information Related to Topic:

Assessment/Curriculum

*STARS, Skills Training for Assertiveness, Relationship and Sexuality.* Building awareness for youth/adult - uses picture assessment for people who are non-verbal.

*Learn About Life.* Curriculum on sexuality and social skills has 6 chapters - your body, my body, being a woman, being a man, having a baby, be safe, and relationships. Each chapter has up to 8 lessons (40 in all). Covers condom use. Spiral bound curriculum, 110 page spiral - bound instructors guide, laminated student resource booklet, one set of cover up stickers to edit material as needed.

*Sexual Education: Secondary Family Life and Sexual Health (FLASH)* A great resource that can provide lessons on communication, puberty, feelings, exploitation preventions and more. Curriculum binder (very thorough) for male and females, addresses homosexuality.

Websites
Sexuality Committee: Checklists/guides for individuals to use to ask their planning teams for assistance in areas for which they have an interest or a need.
http://www.w3ddesign.com/committee/guide.html

Susan’s Sex Site: Especially good for use with people with disabilities, she uses a 4 P’s approach to the topic: Pleasure, Permission, Protection & Privacy
http://www.sexsupport.org

Sexuality Education Resource Manual for Support Workers of People With Developmental Disabilities by Calgary Birth Control Center
http://www.cbca.ab.ca/sexedmanual/tableofcontents.htm

Videos

*Dating: Making Connections*, Stanfield  Where to go, what to say, how to begin relationships, issues covered are unique and fun. Models both successful and troubled relationships.


*Finger Tips*. Video for women. Program for adult females with developmental disabilities. A how to video that models safe and appropriate masturbation.

Slides

*Life Horizons 1*. Physiological and emotional aspects of being male or female. Sex education program for persons with developmental and learning disabilities. Sections include: Parts of the Body, Sexual Life Cycle, Human Reproduction, Birth Control, or Regulation of Fertility and Sexually Transmitted Diseases and AIDS.

*Life Horizons 2*. Focus on attitudes and behaviors that promote good interpersonal relationships and responsible sexual behaviors. Sections include: Building self-esteem and establishing relationships- a male: moral, legal, and social aspect of social behavior. Female: dating skills, learning to love, marriage, and other lifestyles; parenting and/or coping with sexual abuse.

There are many slides in these 2 curricula. Trainer may want to preview and select one or a few slides.
Unit 5: Feedback Exercise

1. What are the three general headings for sexuality training outlined in this unit?

2. Like all other training, goals in the area of sex education should be

3. Give at least four dangers of not providing individual sex education.

4. What is the primary desire of all people, any person?

5. Why does the module suggest that staff use technical language when reporting and teaching but be familiar with street language and common language?
UNIT 6: Facing Issues of Sexual Abuse

Objectives:

After completing this unit staff members will be able to:

- Define and give examples of sexual abuse.
- Understand and provide reasons why individuals with disabilities are more vulnerable to sexual abuse than others.
- Describe ways to prevent sexual abuse.
- Recognize physical and behavioral indicators of sexual abuse.
- Understand feelings and reactions of sexual abuse victims.

Sexual abuse (also referred to as sexual assault and sexual exploitation) can be defined as any sexual activity which occurs as a result of coercion, tricking, physical force, or taking advantage of an individual's disabilities. Sexual abuse is a particular form of physical abuse in which sexual activity is harmful to the individual, emotionally or physically. Sexual abuse, if not directly witnessed, is often difficult to discover. Sexual abuse includes, but is not limited to, any touching or fondling of an individual directly or through clothing for the arousal or gratification of sexual desires. It also includes causing or allowing an individual to touch another person for the purpose of arousal or gratification. It may involve exposure of genitals to shock or scare the victim or obscene phone calls, even though no direct physical contact takes place.

Sexual Abuse Awareness Survey

Try this true/false exercise to help you determine your present basic knowledge in some important areas concerning sexual abuse:

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<tr>
<td><strong>True</strong></td>
<td><strong>False</strong></td>
</tr>
<tr>
<td>1. ____ _____</td>
<td>Sexual abuse is provoked by the victim. People who are sexually abused are asking for it. Rape is the victim's fault.</td>
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<td>2. ____ _____</td>
<td>Anyone can be sexually abused, no matter what they look like or how old they are.</td>
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<tr>
<td>3. ____ _____</td>
<td>Only women are sexually abused. Men are never victims.</td>
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<td>4. ____ _____</td>
<td>People are raped when they are out alone at night, so if individuals stay at home they will be safe.</td>
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<tr>
<td>5. ____ _____</td>
<td>At least two-thirds of all reported sexual abuse cases occur between people who know each other.</td>
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**True False**

6. _____ _____ The victim of a rape is usually threatened with bodily harm if she or he doesn't cooperate.

7. _____ _____ Sexual abuse never happens in suburbs or small towns, only in large cities.

8. _____ _____ Most rapes happen between people of the same race and social status.

9. _____ _____ Most rapes occur because a sexually frustrated man cannot control himself when he sees an attractive woman.

10. _____ _____ Most rapists cannot be easily identified by appearance, dress, or behavior.

11. _____ _____ People often claim to have been sexually abused when it didn't really happen.

12. _____ _____ Marriage gives the partners the right to force sexual contact on their spouse whenever they want.

13. _____ _____ Most rapists feel sorry for individuals with disabilities, and, therefore, would not abuse them.

14. _____ _____ Sexual abuse doesn't affect individuals who have physical disabilities because they don't feel what is happening.

15. _____ _____ People with physical disabilities may be viewed as unattractive and are not likely to be sexually abused.

16. _____ _____ Rape can result in pregnancy.

17. _____ _____ People with disabilities can become involved in sexually satisfying relationships just like everyone else.

18. _____ _____ An individual with a disability does not have the right to sexually abuse another individual.

19. _____ _____ Individuals with disabilities can learn to defend themselves against sexual abuse.

**Sexual Abuse Awareness Survey Key**

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<tr>
<td>1. <strong>False:</strong></td>
<td>Studies show that 60-70 percent of all sexual abuse cases are planned ahead of time. The offender may know in advance who the victim will be or the rapist may decide to find a stranger to assault. Looking nice, dressing attractively, or being alone at night doesn't mean the person wants to be abused.</td>
</tr>
<tr>
<td>2. <strong>True:</strong></td>
<td>Sexual abuse is a violent act. Anyone can be sexually abused no matter what they look like or how old they are. Victims are of any age, size, race, and social class.</td>
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<td><strong>3. False:</strong></td>
<td>There is new evidence to show that men, as well as women, are being sexually abused. It is hard to tell how often this happens because men often don't report the crime, although studies show that one out of every ten males under the age of 18 is sexually abused. Men of any age can be abused. Sexual abuse of men is usually extremely violent and often a weapon is used. These attacks are usually made by men, but women can be offenders, too.</td>
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<td><strong>4. False:</strong></td>
<td>Studies show that one-third to one-half of all sexual abuse cases occur in the victim's home and that over half of all sexual abuse occurs in someone's home.</td>
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<tr>
<td><strong>5. True:</strong></td>
<td>At least two-thirds of all reported sexual abuse occurs between people who know each other (acquaintances). The rapist could be a close friend, family member, neighbor, or anyone else known to the victim. Probably more than two-thirds of offenders are acquaintances because victims are more likely to report sexual abuse if the attacker is a stranger.</td>
</tr>
<tr>
<td><strong>6. True:</strong></td>
<td>In the majority of rape incidents, the victim is usually told she/he will be killed or hurt. A weapon, like a knife or gun, is often used. When a child is sexually abused, threats or bribes are often used to get the child's cooperation. No one wants to be sexually abused.</td>
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<tr>
<td><strong>7. False:</strong></td>
<td>Sexual abuse can happen anywhere - in large cities, suburbs, small towns, and rural areas.</td>
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<tr>
<td><strong>8. True:</strong></td>
<td>Most rapes happen between people of the same race and social status, not between black men and white women.</td>
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<tr>
<td><strong>9. False:</strong></td>
<td>Most sexual assaults are at least partially planned. The offender plans to assault someone or knows exactly who the victim will be. Sexual assault is a crime of violence and hate. During a sexual assault, sex is used as a way to hurt or humiliate the victim.</td>
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<tr>
<td><strong>10. True:</strong></td>
<td>Rapists cannot be easily identified by appearance, dress, or behavior. Rapist act normal, have families, jobs, and friends. However, rapists are more violent than other people. It is this violence that makes a rapist dangerous.</td>
</tr>
<tr>
<td><strong>11. False:</strong></td>
<td>Studies show that only two percent of sexual abuse calls to police are false reports. This is no higher than false reports of other major crimes.</td>
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<tr>
<td><strong>12. False:</strong></td>
<td>Any forced sexual contact between two people is considered sexual abuse, even if the two people are married. No one has the right to force sexual contact on another person, even if the two people have had a sexual relationship in the past.</td>
</tr>
<tr>
<td><strong>13. False:</strong></td>
<td>Most rapists look for people they perceive as vulnerable to attack. Since people with physical disabilities are often seen by the general public as helpless, and since it is sometimes more difficult for persons with physically disabilities to defend themselves, rapists may be more likely to assault individuals with physical disabilities than others. The rapist seeks to gain power over the individual through the attack and sympathy is not an issue.</td>
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<td><strong>14. False:</strong></td>
<td>Some people with physical disabilities have feeling in their lower bodies and some do not. Whether or not the victim can physically feel the abuse, the victim's power has been taken away and the victim will face all of the emotions that other victims experience. It's never okay to abuse anyone.</td>
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<td><strong>15. False:</strong></td>
<td>Persons with disabilities are sexual beings and are sexually attractive. However, rape is an act of violence and aggression, and is not based on the attractiveness of the victim. The sexual act is used as a way to hurt the victim.</td>
</tr>
<tr>
<td><strong>16. True:</strong></td>
<td>Rape can result in pregnancy. Anytime the penis enters the vagina, pregnancy is possible. Victims of rape should go to the hospital to be checked for pregnancy immediately after the assault.</td>
</tr>
<tr>
<td><strong>17. True:</strong></td>
<td>People with disabilities can become involved in sexually satisfying relationships just like everyone else. However, whether an individual is in a relationship or not, rape is a terrifying experience and no one likes that kind of attention.</td>
</tr>
<tr>
<td><strong>18. True:</strong></td>
<td>No one has the right to abuse another person, whether one person has a disability or not.</td>
</tr>
<tr>
<td><strong>19. True:</strong></td>
<td>The best defense against sexual abuse is to learn avoidance techniques, assertive responses, and methods of communication. Depending upon the nature and extent of disability, most individuals can improve their ability to protect themselves.</td>
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Many people still believe the myth that individuals with disabilities are not vulnerable to sexual abuse. They believe that people feel sorry for them and, therefore, will not hurt them, or that sex offenders will see individuals as undesirable and will not abuse them. Others may find the possibility that individuals could be sexually abused so appalling that they are unable to even discuss the issue.

But, individuals with disabilities are even more vulnerable than others to sexual abuse. Studies have consistently found a very high rate of sexual assault against people with intellectual disabilities. Daniel Sorensen (1997) the Chair of the Victims of Crime Committee of the Criminal Justice Task Force for Persons with Developmental Disabilities based in California, reported, that one study found that 83% of women with these disabilities had been sexually assaulted, two additional studies found 86%, while a fourth found 91%. In one of these studies, of the women who had been sexually assaulted, 50% had been assaulted ten or more times. This compares with 13% of women in the general population that will be sexually assaulted at sometime during their life. Sexual assault doesn’t just happen to women with disabilities. One study found that 32% of men with these disabilities in their sample had been sexually assaulted or almost three times the rate of women in the general population.

People with disabilities are at risk for sexual abuse for several reasons:

- Offenders may think it is "safer" to abuse someone with a disability. They may believe that the individual will not understand what is happening; will not be able to defend themselves; or will not be believed. These beliefs may make offenders more likely to victimize individuals with disabilities.
• Generally, individuals with disabilities do not receive the same information about sexual abuse that peers of the same age groups receive. Information available to the general public may not be accessible to people with certain disabilities. For example, there is very little information available in a format that is usable by individuals who are blind. Information presented on the radio or television may not be accessible to those with hearing impairments. There is limited information about sexual abuse that has been adapted for individuals with intellectual disabilities. This lack of information makes it more likely for individuals to misunderstand the crime. Thus, they are more vulnerable to sexual abuse.

• Individuals are often dependent upon professionals and others who provide services and care specific to their disability. This dependence can increase vulnerability to sexual abuse.

• Sometimes, individuals request assistance from strangers who may take advantage of the situation. Or, a stranger may offer assistance solely for the purpose of putting the person with disabilities into situations where they can be abused sexually. An unrealistic view that everyone is your friend may contribute to the development of a very trusting nature about everyone and every situation.

• Overprotection may contribute to a higher risk for abuse. When decisions are always made for someone, s/he may not develop the ability to use sound judgment. Opportunities to practice learning how to make important decisions about who to spend time with and how to handle certain situations may be missed.

• Many individuals with disabilities have not been taught to be assertive or how to refuse. Compliance is reinforced in schools and at home. Not having practice as to when it's advisable to say "no" increases vulnerability.

Some people feel that the best method of decreasing the vulnerability of individuals is to severely limit life activities; i.e. deny opportunities to live independently, participate in community activities, attend evening classes, etc. But shielding individuals from the outside world may lower self-confidence and foster an attitude of helplessness and dependence. While this protectiveness may limit the individual's contact with strangers, it does not protect the individual from abuse by acquaintances, such as friends, family members, and caretakers. Statistics show that in at least 60% of all reported sexual abuse cases, the offender was known to the victim beforehand. For more vulnerable populations, that percentage increases.

**Prevention of Sexual Abuse**

An ongoing training program emphasizing self-reliance is the strongest protection against the vulnerability of sexual abuse. These steps are important in any plan for preventing sexual abuse.
a. Individuals need to be educated about sexuality, positive and negative touching, appropriate and inappropriate social behaviors, their rights, and public/private concepts.

b. There should be regular training in self-advocacy skills, such as, making daily choices, assertiveness, developing awareness of potentially exploitative situations, building self-support networks, speaking for themselves and for their friends who may be unable to speak up for themselves. A teaching program that emphasizes the three-part skill sequence of "Say no - Get away - and Tell someone" is excellent. If an individual feels uncomfortable about a situation, they need to be taught to always tell somebody and to keep telling until someone believes them.

c. Inclusive opportunities are critical for prevention of sexual abuse. Because "separate" service systems, such as large, isolated settings, are often unvisited and therefore unmonitored by the public, the chances of abuse increase.

Obtaining knowledge about sexual abuse is the first step toward its prevention. Therefore, individuals should receive information about sexual abuse and its prevention to the extent that they can comprehend. In addition, individuals should be made more aware of situations where they face increased vulnerability to sexual abuse because of a disability, and should receive positive education and training about preventing sexual abuse in these situations.

Basic topics helpful in a sexual abuse prevention curriculum include:

a. **Vocabulary** - learning words used in discussing the body as well as sexual abuse. Rape is only one kind of sexual abuse. Sexual abuse also includes sexual contact with children by adults, incest, same-sex assault, marital rape, acquaintance rape, exposing of genitals to shock or scare a person, and obscene phone calls. An essential concept is the difference between sexual abuse and healthy sexuality. Individuals need to know that if they are forced, tricked, or coerced into sexual contact, it is sexual abuse.

When discussing body parts, present the technical terms but also accept individuals' expression of their own words for body parts, including street jargon, etc. This may raise their comfort level in discussing sexual abuse, even if they are not familiar with all of the technical terms. However, when correct terms are used when reporting abuse, a person is more "believable".

b. **Touch** - identifying different types of touching and communicating feelings about various touches. There are all types of touch, from nurturing touch, to confusing touch, to negative touch, to lack of touch.

Lack of touch can be positive or negative. If a person wants and needs touch, but is denied touch, this lack of touch can be negative. However, if a person does not want to be touched, lack of touch can be positive. Nurturing touch is touch that feels like something is being given or shared. Hugs, kisses, and handshakes may be examples of good touch. Confusing touch is any touch that
cannot be clearly labeled positive or negative. Any touch may become confusing when:

- the meaning of that touch is not clear
- a double message is received
- the receiver is not accustomed to touch or doesn't want to be touched
- the touching becomes sexual and the receiver is confused about it

Negative touch is touch that is painful, or feels like something is being taken away. The receiver feels hurt or used. Kicks, hits, slaps, and sexual abuse are examples of negative touch.

The same touch can be positive or negative depending upon the individual and the situation. Thus, there may be some disagreement about whether certain touch is positive, confusing, or negative during group discussion. Role-playing assertive responses to the negative touch situations such as saying "no", getting away, etc. is an effective means of practicing in a safe environment. However, discussion should also focus upon individuals' feelings about different touches as well as upon assertive responses.

c. **Myths and Facts About Sexual Abuse** - learning factual information about sexual abuse. The issues of sexuality and sexual abuse are so shrouded in myths and misconceptions that it may be difficult to determine what is true and what is not. Unfortunately, sometimes information about sexual abuse through the media, tends to support commonly held myths and popular opinions. Educational materials dispelling the myths providing factual information are available. Education is important in preventing and dealing with instances of sexual abuse.

During discussions, be aware that people can become programmed to give the right answers while still believing the myths. For example, one may say that sexual abuse is not the victim's fault, but still believe that a woman who allows a man she just met to take her home is asking to be raped. It is important to respond to statements that imply sexual abuse is the victim's fault, and that the offender is not to blame for the attack, even if the victim did use poor judgment. The victim's behavior or dress does not make him/her responsible for the sexual abuse.

d. **Sexual Abuse by Acquaintances and Family Members** - introducing realistic situations where sexual abuse could occur. If the previous topics have been addressed, individuals should be relatively comfortable with the information covered up to this point, and should be familiar with common myths and facts. However, many may still think of sexual abuse in terms of strangers. Being confronted with realistic situations in which the abuser is someone previously known by the victim can be frightening. Discomfort with the topic may be indicated by fidgeting, embarrassment, withdrawal or unusual misbehavior.

e. **What If Someone Is A Victim?** - reviewing basic information about reporting sexual abuse, the medical examination (if required), prosecution, community resource people, and people identified who can be told about the sexual abuse.
Since sexual abuse does frequently go unreported and because it is often difficult to detect, it is helpful to know the physical and behavioral indicators that sexual abuse may have occurred. Indicators that a person may have been abused include:

- Difficulty in walking or sitting
- Torn, stained, or bloody underclothing
- Pain or itching in the genital area
- Bruises or bleeding in genital or anal area
- Venereal disease
- Pregnancy
- Difficulty sleeping, or sudden and frequent nightmares/sleep disturbances
- Avoidance of a previously trusted and well-liked person, especially anyone in a position of authority
- Unexplained stomachaches or change in eating habits
- Fear of being left alone, or the unusual desire to be alone (withdrawal)
- Sudden infantile behavior (sucking, biting, rocking, bedwetting, etc.)
- Change in leisure habits, or reluctance to join in previously enjoyed recreational activities
- Delinquency or running away
- Bizarre, sophisticated, or unusual sexual behavior or knowledge
- Hypochondria
- Refusal to undress, to bathe, or to be bathed
- Depression
- Self mutilations
- Excessive masturbation
- Poor self-image

Answers to the following questions will help staff members be prepared in advance of possible sexual abuse situations:

- Does the local police department have a special unit that handles sexual abuse crimes?
- If needed, is there a certain hospital best for victims to use?
- How does the hospital handle rape cases?
- Does the court system have a program to assist and support victims who decide to prosecute?
- Is there a sexual abuse center in the community? If so, what services are provided? If not, where else can victims go for help?
- When does Protection and Advocacy Project need to be involved and who is responsible for contacting them?
Answers to these questions can be obtained from the local sexual abuse center, law enforcement agency or a Protection and Advocacy project.

f. **Reactions and Feelings of Sexual Abuse Victims** - awareness of the feelings of sexual abuse victims during and after the abusive situation. Again, realistic episodes where sexual abuse has occurred can be presented through role-play or discussion. The focus should be on how victims feel during, directly after, and days, weeks or even years after the abuse. There may be no right or wrong answers, but the discussion should allow individuals to explore their feelings.

Be sure to emphasize that victims can be both male and female. Responses of males may differ from those of females. Males may tend to deny that sexual abuse could happen to them, minimize feelings about the abuse, etc.

g. **Personal Safety** - guarding against sexual abuse. Individuals may be accustomed to thinking about avoidance techniques to prevent sexual abuse by strangers, but not to develop techniques for prevention of sexual abuse by family or acquaintances. Focus discussion and role-plays on prevention of abuse by both stranger and acquaintances. Discussion should be focused on avoidance and telling rather than self-defense.

h. **Assertiveness** - identifying and practicing assertive responses. Assertiveness is one of the most important skills that an individual can learn to prevent sexual abuse. Individuals are often in situations where they must act assertively by obtaining or refusing help from strangers, asserting themselves with family, friends, service providers, etc. Learning to be assertive will greatly enhance feelings of self-worth and assist in building relationships, as well as help individuals to avoid potentially dangerous situations.

Assertiveness can be defined as thinking, speaking, and acting on a person's own thoughts, feelings and desires, taking into account the wishes and feelings of others. It is a way of standing up for the person's own rights without violating the rights of others. Assertive behavior does not always bring the desired result, but it is worthwhile in that it allows the individual to state what he/she wants or thinks.

**Aggressiveness** involves violating the rights of others, or showing them no respect. It includes sarcasm, insults, or intimidation to win or dominate.

**Passiveness** means giving into other people's requests, demands or feelings, without regard to one's own wishes or feelings. Passive behavior is based on the belief that other people's feelings, opinions, and desires are more important, or that an expression of an individual's feelings will result in punishment. Passiveness is often expressed by silence. It is this type of behavior that can lead to sexual abuse, especially by acquaintances. Refer to Interpersonal Communication module (895.60) for more information.

Some examples of assertive, aggressive and passive behavior follow:
1. Someone tries to give you a hug after a football game and you don't want to be hugged.

**Assertive response:** "I like you, but I don't feel like being hugged today."

**Aggressive response:** "Get your hands off me. You are a real slob, and I don't like you."

**Passive response:** Say nothing and allow the person to hug you because you don't want to hurt the person's feelings.

2. You are at a party. You are ready to leave, but your friends do not want to leave yet.

**Assertive response:** Tell your friends that you would like to go home. If they are not ready, you can decide to wait for them, go home with a friend or someone else you trust, or call your parents or a taxi. (Note: Even though you express your feelings about wanting to leave, your friends may still insist on staying).

**Aggressive response:** Insist that your friends drive you home immediately, regardless of their desires. Keep bothering them until they take you home.

**Passive response:** Do not tell your friends that you are ready to go, because you do not have the right to state your desires since you didn't drive. Wait patiently until your friends are ready to leave.

It is important to note that a program in sexual abuse prevention should not take the place of sex education. Ideally, a complete approach would include both areas of instruction. Specific needs should be addressed through the individual's plan.

**Guidelines for Sexual Abuse Prevention Training**

Staff members should:

a. **Be aware of their personal comfort level in dealing with sexual abuse.** Many people, including teachers and other professionals, feel uncomfortable discussing the issue of sexual abuse. However, a thorough review of curriculum materials, background reading, and contact with sexual abuse centers or other community resources should increase one's comfort level.

b. **Utilize a person from a sexual abuse center or other community agency as a resource.** It is recommended that agency staff present the material, utilizing someone with expertise in the area of sexual abuse such as a representative of a sexual abuse center, social worker, police officer, or advocate as a resource. The sexual assault resource person can answer questions that arise in class, explain available community resources, assist with instruction, or work with those who have been sexually abused. Familiarity with the issue
can determine to what extent outside resources are utilized.

c. **Offer sexual abuse prevention training in the most appropriate setting.** This training may be included in a course on sexuality, home and family living, public safety, personal growth and development or any other course deemed appropriate. Residential facilities, training centers, retreats, or special summer programs for individuals are examples of appropriate settings.

d. **Be flexible in your approach.** Modify a curriculum to meet the needs of individuals. If working with people with multiple disabilities, or in a situation where a variety of disabilities are represented, it may be best to select portions to offer based on team recommendations. Flexibility is the key to meeting individual needs.

e. **Do research on existing community resources beforehand.** What are the police reporting procedures in your community? What hospitals are best equipped to handle sexual abuse evidentiary examinations? Is there a sexual abuse crisis center? What other community services are available? Obtain names and telephone numbers of contact persons.

f. **Deal with embarrassment early in the discussion.** Many people are not used to dealing with sexuality or sexual abuse issues and may feel embarrassed. This embarrassment may be expressed through giggling, laughing, silliness, or silence. Stress the importance of acquiring knowledge about sexual abuse and the serious nature of the crime. Also stress that what individuals disclose inside the group should not be discussed outside of the group.

g. **Stress that anyone is vulnerable to sexual abuse.** Because many materials emphasize the vulnerability of individuals with disabilities and address specific situations which individuals face, the danger exists that they will conclude that persons without disabilities are never victimized. Stress that anyone is vulnerable to sexual abuse, including individuals with disabilities.

h. **Think about how you will talk to a person who discloses sexual abuse.** Staff are not responsible for being the investigator, prosecutor, judge, or therapist in sexual abuse cases. Follow your agency policies to determine your role in the event of a disclosure. The individual will look to you for support and information. Here are some general guidelines for responding to a victim:

*Believe* - It is possible that a victim will disclose information at an "inappropriate" time, therefore, may not be taken seriously. It is also possible that the person will not have all the details straight and, therefore, is discounted or not believed. It is unlikely that a person will make up a sexual abuse experience. Sexual abuse is often very embarrassing and difficult to talk about. Therefore,
accusing someone of committing a sexual assault is not an easy or likely way to "get back at someone".

Language - The person may not know the correct terms for body parts or actions. Let them point and use slang terms to describe what has happened.

Affirm - Acknowledge the importance of talking about the abuse and getting help. Do not assume that the individual knows she/he should talk about it.

Support - Remain neutral in your reaction. Showing shock or disgust will only increase the person's anxiety.

Avoid Judging - Avoid "why" questions (Why did you talk to that stranger?", "Why didn't you tell me before?") Even if someone was tricked or manipulated into doing something they "should have known better than to do", the abuse is not their fault; the tricks and manipulations are part of the abuse and victimization process. Reinforce that a person who has been victimized was forced, tricked, or manipulated and, therefore, is not to blame.

Empower - A victim of sexual abuse often feels helpless and powerless. By affirming and supporting her/his feelings, listening to her/his concerns, fears and needs and educating her/him about available resources, the victim is empowered with a sense of all the options available to her/his ability to no longer be a victim.

Refer - According to your agency's policies and procedures, help the individual receive appropriate services through referral to helpful support groups or agencies.

Feelings and Reactions of Sexual Abuse Victims

The specific reactions and feelings of each victim of sexual abuse will vary depending upon the degree of force used during the assault, the victim's relationship with the assailant, the circumstances of the abuse and the victim's pre-established pattern of dealing with life crises. Studies show that victims have similar reactions and feelings to sexual assault. These feelings are presented as follows:

a. Fear - Anxiety Reactions. Although the specifics of each sexual abuse situation are different, many victims respond initially with a feeling of relief, "Thank God I'm alive - I could have been killed." This realization often creates a feeling of fear of being attacked again. This fear response may be a specific fear of the assailant, especially if the assailant threatened to harm the victim again, or it may be generalized fear; fear of people or things that remind the victim of the assault situation. Many victims will experience feelings of anxiety based on their fear of being attacked again. This anxiety may be observed as shaking, startled reflexes, disturbed sleeping patterns, and nightmares. This anxiety may extend to a fear of people in general. The victim may be particularly attuned
to sexual innuendoes, and glances that used to be taken in stride. If the assailant was someone trusted by the victim, she/he may experience a feeling of loss of faith and trust not only in others but also in her/his own judgment.

Many victims may have believed, prior to the sexual assault, that sexual assault couldn't happen to them or that they would be able to resist or somehow take care of themselves. Since any resistance was overcome either by force or fear, most victims may feel a loss of control. They may experience feelings of powerlessness and helplessness that affects the way they view their own independence. If the victim has followed a lifestyle of trusting people, leaving doors open, talking to strangers, hitchhiking across country, and so on, the sexual assault may be felt as an intrusion not only of the body but of her/his whole way of life.

b. Guilt - Self-Blame - Embarrassment. In general, feelings of guilt and self-blame seem to vary in degree with the circumstances of the sexual assault, the extent of physical injury to the victim and the type of association with the assailant. Victims who have experienced severe physical injury during the sexual assault usually have less guilt feelings because of the obvious evidence of their resistance. The victim who was sexually abused at home, however, may feel guilty about not having secured the house better. The victim who knows the assailant may have the most difficulty in resolving guilt feelings and conflicts over the sexual abuse. This victim may irrationally blame her/himself for poor judgment or seductive behavior. The victim who does not physically resist due to fear may irrationally blame her/himself for not preventing the abuse - even if physical resistance would have been useless. Many victims may feel ashamed and embarrassed about the sexual abuse due to society's discomfort with sexuality in general. Our bodies and sexual activity have always been regarded as private. The assault has stripped the victim of their privacy. Telling anyone at all may be painful and embarrassing. If the assailant was verbally abusive, the victim may be embarrassed to repeat what was said. In addition, the victim may not know acceptable terminology to describe what happened sexually. The victim may also feel embarrassed during the medical exam when her/his body is again exposed and is the object of attention and inspection by strangers.

c. Anger. Anger is perhaps the most appropriate feeling the victim of sexual abuse can experience. Anger, directed toward the assailant, can be the beginning of a healthy resolution of the sexual abuse experience. Many victims may have difficulty expressing this anger verbally, although ventilation of the anger may also take the form of reporting and prosecuting.
Curriculum Resources and Information Appropriate to Topic

*No-Go-Tell.* Easy to teach lessons in child protection, teaches concepts: who are family, friends, familiar people, and strangers - What is "OK" touch and "Not OK" touch? What are private parts? Who and how to tell about an abusive incident. Although made for children, this may be appropriate to use with some adults. At the very least, the material is excellent for staff to become familiar with this topic. This approach of No-Go-Tell is appropriate to teach at any age and is used in Sexuality Series III and Date Smart Part 4 & 5 videos.

*Circles.* Video and other miscellaneous materials addresses physical proximity for self-protection.
Unit 6: Feedback Exercise

1. Give at least three reasons why individuals with disabilities tend to be more vulnerable to sexual abuse in our society.

2. Three common feelings or reactions to sexual assault are __________, ___________ and __________.

3. It has been estimated that more than ______ of all perpetrators of sexual abuse were previously known to the victim with a developmental disability.

4. Obtaining __________ about sexual abuse is the first step toward it's __________.

5. Because sexual abuse frequently goes unreported, it is important to be aware of possible physical and behavioral indicators that it may have occurred. Name at least five potential indicators.

6. Describe staff guidelines for sexual abuse prevention training:

7. What are the basic topics in a sexual abuse prevention curriculum?

8. What should staff do, when a person receiving services discloses sexual abuse?
UNIT 7: Learning About Sexually Transmitted Disease

Objectives:

After completing this unit staff members will be able to:

- Understand and describe sexually transmitted diseases and provide ways of prevention and treatment.

Years ago, a discussion of Sexually Transmitted Diseases (STDs) or venereal diseases, would have focused primarily on syphilis and gonorrhea. During the 1980s, the focus broadened to include herpes, chlamydia, and AIDS. Now, the attention of the public, as well as that of the health care community, is primarily focused on AIDS. Some discussions of STDs today might even be limited to that disease. For the welfare of staff and individuals served, it is critically important that staff members be as well informed as possible about AIDS. It is a dangerous, deadly disease. However, all of the STDs mentioned above are a real threat; in fact, some have been on the increase simply because too many people believe they have been eliminated. This is not meant to be a complete list of all STDs. There are others not listed here. The point is, there are many types of STD, and many are very dangerous. ANY sexually active person could be at risk of contracting any one of these STDs.

A program of education or training in sexuality to individuals who are or who may become sexually active must include a frank, factual presentation of what is known about STDs, how they are acquired and how they can be prevented, and what, if need be, can be done to cure them. Teams should assist direct support staff in developing teaching strategies appropriate to the individual’s level of understanding. All staff should present consistent information about prevention and support individuals in taking appropriate precautions, if they are sexually active. When staff become aware that an individual is sexually active and is not taking appropriate precautions to prevent STDs, they should follow agency policies and procedures. If there are no specific policies related to at risk sexual behavior, document the behavior and follow policies that are indicated for other risky health behaviors.

This chapter will provide an overview of the symptoms, effects, prevention, and cure of the more common STDs. This overview, should not be considered a substitute for ongoing education. This chapter is an invitation to establish and maintain contact with a health care provider or community health service. There are volumes of information available, and any number of resource people. In this case, ignorance is not bliss.
AIDS

AIDS is the STD that has been the focus of public attention in recent years. Public attention sets that stage for education and prevention, but it can also generate a lot of misinformation, fear, and needless anxiety. AIDS is an acronym for Acquired Immune Deficiency Syndrome. The disease breaks down of the body's natural ability to fight off disease and infection. This leaves the body vulnerable to a range of illnesses, which would normally not be a major concern. However, it is these diseases, not AIDS itself, which kill. The most common illnesses found in people with AIDS are Pneumocystis carinii pneumonia, an infection of the lungs, and Kaposi’s sarcoma, a form of cancer.

AIDS is the final stage of a long and complicated infection caused by a virus called HIV (Human Immunodeficiency Virus). It is this virus which attacks and destroys the body's normal immune system. The presence of this virus DOES NOT mean that the infected person has AIDS, but EVERY person infected with the HIV virus is capable of passing it on to someone else. Many of those infected with HIV will remain in good health for years. Others may develop a range of illnesses, from mild to serious, called collectively ARC (AIDS Related Complex). However, it is important to realize that even if a person infected with HIV does not develop AIDS or ARC, that person is still capable of infecting others with the virus.

Transmission. Because it is virtually impossible for the HIV virus to survive outside of the body, AIDS is a relatively difficult disease to catch. The means of transmission are limited and clearly defined. They are:

1. Sexual contact with an infected partner, involving the exchange of blood, semen, and/or vaginal fluids.
2. Sharing needles with an infected intravenous drug user.
3. Receiving a transfusion of infected blood. Since 1985, all blood donated to blood banks is tested for the antibody to HIV. This has greatly increased the safety of receiving a blood transfusion.
4. Infected pregnant women may transmit the virus to their babies before or at the time of birth.
5. Infected nursing mothers MAY transmit the virus through their breast milk.

The HIV virus is NOT transmitted through doorknobs, toilet seats, shaking hands, drinking cups, mosquitoes, donating blood, or other casual contact.

Symptoms. Essentially, they are the symptoms of the diseases mentioned previously. Included might be unexplained and increasing tiredness, unexplained fevers, chills or night sweats, swollen glands lasting over several weeks, sudden or extreme weight loss, (greater than ten pounds, not due to dieting), white patches or spots on tongue or mouth, persistent diarrhea, dry cough not due to smoking or minor ailments, pink or purple flat or raised blottches that don't go away on or under the skin, in the mouth, nose, eyelids or anus. Each of these symptoms can be caused by something other than AIDS, but they do indicate that testing should be done.
Effects. Simply enough, for those HIV carriers who do develop AIDS, the disease is always terminal.

Treatment. Although much research is being done and there are treatments which show promise, there is no cure for AIDS at this point. As advances are made in the treatments of HIV- associated illness and immune disorders, it becomes increasingly beneficial for people infected with HIV to know early whether or not they have the disease. Early detection will allow the health care provider to advise health practices which may prolong life.

The full effects of HIV infection (AIDS) may appear 5-15 years or more after the original infection with the virus. The full disease state of AIDS is associated with life-threatening infectious diseases and cancers. Health care professionals can help to ease the symptoms and prolong the life of the AIDS patient.

Gonorrhea

Gonorrhea is a painful and dangerous disease caused by an organism called gonococcus. Every year, about a million people in the United States contract this STD. Some of the common slang names for gonorrhea are "clap", "strain", "gleet", "morning drop", "a dose", and "the whites."

Transmission. Gonorrhea, like all STDs, is transmitted through intimate sexual contact, that is, intercourse, or close body contact involving the genitals, mouth, and/or rectum. Intimate contact is necessary for the transmission of gonorrhea because, as with most STDs, the organisms causing these diseases die very quickly when exposed to light and air away from the warm, moist areas of the human body.

Symptoms. Gonorrhea symptoms usually appear two to eight days after infection, beginning with an itching or burning in the sexual organs, especially while urinating. A woman may experience a whitish vaginal discharge, fever or abdominal pain, or she may have virtually no symptoms at all. It has been estimated that as many as eight out of ten women infected do not notice any signs or symptoms, and may not know they have been infected unless their partner tells them. A man will typically see a whitish discharge from his penis, though it is possible that as many as 20 to 30% of men infected will display no symptoms, either.

Effects. Gonorrhea, if left untreated, can cause sterility in both male and female, peritonitis, arthritis, heart trouble and/or blindness. A pregnant woman with untreated gonorrhea can infect her unborn child, and blindness in the child is a real possibility.

Treatment. Gonorrhea responds readily to medication, usually penicillin, and the disease is curable. But treatment must be given early if the disease is to be prevented from damaging the body. Penicillin cannot repair damage already done. It is critically important that when reporting for treatment an infected person give the doctor or health care professional a complete list of his or her sexual partners, so that they too can be notified
and treated. Those infected with Gonorrhea, as with ALL STDs, do not build up immunity to the disease, and are subject to re-infection again and again.

**Syphilis**

Syphilis is a disease caused by an organism called Treponema pallidum. Some common slang names for syphilis are "pox", "siff", "lues", "bad blood", and even "Old Joe."

**Transmission.** Syphilis is transmitted through intimate sexual contact, or close physical contact, such as kissing, if there is a lesion or chancre in the mouth.

**Symptoms.** The first sign is usually a sore which appears 10 to 90 days after infection, at the point the germs entered the body, (typically the sex organs or mouth). This first sore is called a "chancre" (pronounced "shanker"), and may look like a pimple, blister or open sore. The chancre may be so small that it isn't noticed. This is especially true in females, because the sore may be hidden in the folds of genital tissue. The first chancre will disappear, even without treatment, but the disease has not run its course at this point.

Three to six weeks later, the person may develop a rash on part of the body, sores in the mouth, fever, headache, sore throat, falling hair, or all of these. This is the secondary stage of syphilis. And again, the signs may be slight and difficult to notice, and they too will subside even without treatment. The disease, however, remains active in the body of the infected person.

After about two years, a person with untreated syphilis reaches a point at which he or she cannot infect others, but their own health is still in great danger. The greatest damage can take years to surface. Left untreated, syphilis spreads to all parts of the body, and can cause blindness, insanity, heart disease, paralysis, deformity, and death. An overall rate of one in twenty-five of those afflicted and not treated will become in some way permanently crippled or incapacitated due to syphilis. The child of an untreated pregnant woman can be born deaf or blind or mentally retarded. The child may seem to be sound at birth but later develop problems. Syphilis is an extremely dangerous and damaging disease, and has been for centuries.

**Treatment.** Syphilis responds to treatment, generally penicillin, and can be cured. If treated early enough, permanent damage to the body can be avoided. Again, however, no immunity is developed, and re-infection is a possibility.

**Herpes** (More specifically, Herpes Simplex virus type 2 (HSV-2).)

**Transmission.** This strain of the herpes virus is a sexually transmitted disease, (there are herpes strains which are not) and is passed along through intimate sexual contact with an infected person. In addition the disease can spread by direct contact with an infected area, transmitting the virus to another site on the body.
Symptoms. The sores of herpes virus infection generally develop 3 to 7 days after infection, often beginning with burning or tingling, especially during urination. These are usually raised sores or fluid-filled blisters which either spontaneously resolve or rupture to form shallow, often painful sores which then heal over. The lymph nodes in the groin may swell and become tender. The initial infection lasts from 14 to 28 days. Women tend to have more discomfort than men, though infection of the cervix or vagina does not always cause symptoms.

Even though the sores go away, the virus remains in the nerve tissue of the body and can cause recurring flare-ups. Recurrences are very unpredictable, and may be triggered in some by fever, sunlight, menstruation, or emotional stress. The sores of recurrent infection generally last from about 7 to 14 days.

Effects. Studies suggest that herpes genital infection predisposes women to cervical cancer, at perhaps a level of five times greater risk. A pregnant woman with active genital herpes can infect her baby during delivery, and even before, though that is rare. If delivered through an infected birth canal, a baby has a 40 to 50 percent chance of being infected. The mortality rate from herpes in the bloodstream of infected babies may be as high as 50 percent. To prevent contact with an infected birth canal, a mother may need to have her baby by cesarean section.

Treatment. While it is true that there is no well-documented, safe reliable cure for herpes, there is an effective, FDA approved treatment that will reduce the length or even prevent both primary and recurrent symptoms. It is called Acyclovir, an antiviral compound available as both a topical creme, and an oral medication. Most clinicians also recommend soaks to keep the infected area clean, drying agents to hasten healing of the lesions, and analgesics when needed.

Chlamydia

A little known but very widespread STD, caused by the bacterium Chlamydia trachomatis. Chlamydia, which can resemble a mild case of gonorrhea, is estimated to be the most common STD in the United States.

Transmission. Chlamydia is spread through intimate sexual contact.

Symptoms. Chlamydia symptoms resemble those of gonorrhea, but are usually milder, and may even be absent. It has been estimated that 60 to 80 percent of women and 10 to 20 percent of men infected have no symptoms at all. Women may notice itching or burning in the genitals, dull pelvic pain, and bleeding between menstrual periods. Men may notice a painful, burning urination, and a watery discharge from the penis.

Effects. Like gonorrhea, chlamydia left untreated can cause pelvic infection, arthritis and eye infection. In men, the bacterium can cause inflammation of the urinary tract, and of the testicles, leading even to sterility. In women, chlamydia can cause cervical infection, spreading to the uterus and fallopian tubes, resulting perhaps in pelvic inflammation, infertility, and an increased risk of tubal pregnancy. An infected pregnant woman can pass the bacterium to her baby during
birth, causing an eye infection called conjunctivitis, and pneumonia. The risk of spontaneous abortion and stillbirth is much higher in women with chlamydial infections during pregnancy.

Treatment. Chlamydia responds to treatment with antibiotics, and is curable. As always, it is important that detection and treatment begin early.

Prevention of STDs

While it is true that some of the STDs reviewed in this unit respond to treatment, and most can even be cured, it is simple common sense to emphasize that prevention is by far the preferable stance. And the point to be emphasized most strongly is that sexually transmitted disease can indeed be prevented.

Abstinence. First and most obviously, of course, sexually transmitted disease is most dependably avoided by those who choose not to be sexually active. Because the transmission of these diseases depends upon intimate sexual contact, if there is no such contact, the risk of contracting one of the diseases is virtually eliminated. It remains true that abstinence is a safe course.

Exclusive Relationships. For those who do choose to be sexually active, however, there are a number of steps that can be taken to minimize, if not eliminate, the risk of contracting an STD. Next to abstinence, the safest sort of sexual relationship is a mutually monogamous (one sexual partner) relationship, with a partner whom you know is not infected, and not engaging in sexual activity with other people. As the number of sexual partners increases, so does the risk of sexual disease.

But whether one or many, it is very important to know your partner as well as you possibly can. Know their habits, their style of personal hygiene, and their friends. No one should be hesitant about questioning a potential sexual partner as to his or her health and habits.

Male and Female Condoms. Certainly the most familiar preventative method, and an effective one, is the use of a condom (also known as a "rubber" or "safe"). Used properly and conscientiously, the condom can substantially reduce the risk of STD. To realize the condom’s fullest potential as an STD preventative, it must be used each time a couple has intimate sexual contact. This is especially so when either partner cannot be absolutely certain that the other has not been with another sexual partner. Moreover, the condom must be used from the very beginning of sexual contact. Many times couples will wait until just before ejaculation before putting on the condom, but by that time, both partners have already been exposed. STD germs and viruses are passed from partner to partner not only in the sperm, but in pre-ejaculate secretions from the male, and in vaginal secretions from the female.

The manufacture of condoms is subject to regulation by the FDA (Food and Drug Administration), and familiar brand name products are considered reliable. However, it is true that over the past few years, due in part perhaps to an increase in demand, poorly made, very
unreliable condoms have appeared on the market, and of course, the use of such is no protection at all. It is worth emphasizing that the individuals we serve should be taught in this matter to deal only with a known and trusted pharmacy. It is more than likely a mistake to deal with mail order companies, and it is a risk to accept a condom from another person, even if the packet seems intact. As an added measure of protection against infection, given the possibility of even a brand name product tearing or breaking, withdrawal before ejaculation should be described as an option. One final emphasis should be made with regard to condoms. The fact that a condom is not only an STD preventative, but a birth control device as well, has led to confusion in the minds of some as to the value of other birth control methods as an STD preventative. It is important to make the point to the individuals we serve that neither a diaphragm, nor an IUD (Intrauterine Device), are of any such value at all. However, there is a spermicidal jelly, Nonoxynol-9, which, when used together with a condom, has been shown to be an effective aid in preventing sexually transmitted disease.

So, again, used regularly and properly, the condom is an effective, simple-to-use means of preventing STD. So much so in fact that the use of a condom has come to be virtually synonymous with "safe sex".

Sexual intimacy other than intercourse. Mention should be made of another choice that has been given emphasis lately in Human Development training programs, often in the face of some controversy. That is to choose sexual activity that does not involve direct contact between the genitals, or genitals and mouth or anus. If there is no exchange of body fluids, including blood, semen, and vaginal fluid, the risk of contracting STD is markedly decreased. Pleasure, satisfaction, and affection can be safely and effectively shared through mutual touches and caresses (though even here it is worth emphasizing the wisdom of preventing sperm, blood, or genital secretion from coming into contact with a cut or lesion on the hand, or any part of the body).

It is simply a fact that in our culture, "sexual intimacy" is presumed to mean intercourse. That is an unfortunately limiting presumption, and may well put unwelcome pressure on those for whom intercourse is either physically difficult, (as may be the case with some of the individuals we serve), or on those for whom, for whatever reason, intercourse is not a positive option. It is worth emphasizing that such a choice is a valid one, and that a satisfying, pleasurable, intimate relationship can be enjoyed and maintained without intercourse.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Contact to First Symptoms</th>
<th>Usual Symptoms</th>
<th>Diagnosis</th>
<th>Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>GONORRHEA (Also called dose, clap, drip) Cause: Bacterium</td>
<td>2-10 days sometimes 30 days</td>
<td>Local, genital discharge, pain; often no symptoms in men; usually no symptoms in women</td>
<td>Examination, smear for men; culture for women</td>
<td>Pelvic inflammatory disease, sterility, arthritis, blindness, eye infection in newborns.</td>
</tr>
<tr>
<td>SYPHILIS (Also called syph, pox, bad blood) Cause: Spirochete</td>
<td>3.5 weeks; average 21 days</td>
<td>First stage: painless pimple that disappears without treatment on genitals, fingers, lips, breasts; Second stage: rash, fever, flu-like illness; Latent stage: none</td>
<td>Examination, blood test</td>
<td>Brain damage, insanity, paralysis, heart disease, death, damage to skin, bones, eyes, liver, teeth of fetus and newborns.</td>
</tr>
<tr>
<td>Disease</td>
<td>Contact to First Symptoms</td>
<td>Usual Symptoms</td>
<td></td>
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<tr>
<td>---------------------------------------------</td>
<td>---------------------------</td>
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<tr>
<td>AIDS (Acquired Immune Deficiency Syndrome)</td>
<td>From 6 months to an unknown period of time. Average is seven years or more.</td>
<td>Many people may look and feel fine for many years after HIV infection occurs. The symptoms of HIV infection are the symptoms of the diseases that attack the body because of a weakened immune system (i.e., fever that lasts from a few days to longer than a month, excessive sweating, especially at night; loss of appetite; chronic or long lasting fatigue; weight loss of more that 10% of body weight; muscle and joint pain; long lasting sore throat; swollen lymph glands; diarrhea lasting longer than a month.</td>
<td></td>
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<tr>
<td>HERPES PROGENITALS</td>
<td>About 1 week</td>
<td>Swollen, tender, painful blister on genitals.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NON-SPECIFIC VAGINITIS</td>
<td>1-2 weeks</td>
<td>Gray offensive vaginal discharge, usually no itching</td>
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</tr>
<tr>
<td>NON-SPECIFIC URETHRITIS</td>
<td>1-2 weeks</td>
<td>Local discharge, frequent urination; often no symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCABIES</td>
<td>4-6 weeks</td>
<td>Severe nighttime itching, raised gray lines in skin where mite burrows.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TRICHOMONAS</td>
<td>1-4 weeks</td>
<td>Discharge, intense itching, burning and redness of genitals and thighs; painful intercourse; usually no symptoms in men</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VENEREAL WARTS</td>
<td>Up to 2 months</td>
<td>Local irritation, itching</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PEDICULOSIS PUBIS</td>
<td>4-5 weeks</td>
<td>Intense itching, pinhead blood spots on underwear, small eggs or nits on public hair</td>
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<td></td>
</tr>
<tr>
<td>CHANCROID</td>
<td>1 day to 2 weeks; average 4 days</td>
<td>Painful sores on the genitals; also, swollen tender gland in the genital area, usually one side only</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>A blood test called the &quot;HIV Antibody Test&quot;</td>
<td>As the number of white blood cells declines, the immune system becomes less and less able to protect itself against a variety of illness. The infected person becomes more susceptible to opportunistic infections or cancers that attack the body and can cause death.</td>
</tr>
<tr>
<td>Pap smear, examination, culture</td>
<td>Strong evidence linking infection to cervical cancer; severe central nervous system damage or death in infants infected during birth.</td>
</tr>
<tr>
<td>Examination, smear, culture</td>
<td>Medical complications unknown.</td>
</tr>
<tr>
<td>Examination; negative tests for gonorrhea</td>
<td>Medical complications unknown.</td>
</tr>
<tr>
<td>Examination</td>
<td>May infest elbows, hands, breasts and buttocks as well as genitals.</td>
</tr>
<tr>
<td>Pap smear, examination, urinalysis</td>
<td>Gland infections in females, prostatitis in men.</td>
</tr>
<tr>
<td>Examination</td>
<td>Highly contagious; can spread enough to block vaginal opening.</td>
</tr>
<tr>
<td>Examination</td>
<td>No medical complications.</td>
</tr>
<tr>
<td>Examination, smear, culture</td>
<td>Scarring, permanent deformity.</td>
</tr>
<tr>
<td>Disease</td>
<td>Contact to First Symptoms</td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>GRANULOMA INGUINALE (Donovaniosis)</td>
<td>1-10 weeks</td>
</tr>
<tr>
<td>LYMPHOGRAVALLOMA VENEREUM (LGV, Frei's disease)</td>
<td>3 days to 3 weeks; average 10 days</td>
</tr>
<tr>
<td>MONILIA (also called monilias, vaginal thrush, yeast, candidiasis)</td>
<td>Varies</td>
</tr>
</tbody>
</table>

Consultant: David Schlossberg, M.D., Polyclinic Medical Center, Harrisburg, PA


For additional information call or National V.D. Hotline 800-227-8922

**Curriculum Resources and Information Appropriate to Topic**

**Curriculum:**

SAFE (Stopping AIDS Through Functional Education) curriculum package includes instructional materials on preventing HIV/AIDS, for people who have developmental disabilities or other learning problems. (Most community-based providers in North Dakota have a copy.)

**Slides.**

Life Horizons 1 has a section on HIV, Aids and STDs.

**Websites:**

*Sexual Health Network*, good general disability site with a lot of info and advice, use search option for section on DD info: [http://www.sexualhealth.com/](http://www.sexualhealth.com/)

Sexuality & Disability Bibliography site: [http://www.iidc.indiana.edu/cedir/sexuality.html](http://www.iidc.indiana.edu/cedir/sexuality.html)

Sexuality & Disability Webliography with Links to other sites, [http://www.bccpd.bc.ca/wdi/sex_dis_webliog/dd.html](http://www.bccpd.bc.ca/wdi/sex_dis_webliog/dd.html)
UNIT 7: Feedback Exercise

1. STD stands for_______________________________.

2. An STD is spread by_______________________________.

3. Sexually transmitted diseases can be_______________________________.

4. What is the most effective method to prevent transmission of sexually transmitted diseases?

5. List other ways to prevent the transmission of STDs.
UNIT 8: Considering Birth Control Options

Objectives:

After completing this unit staff members will be able to:

- Understand the complexity of decisions concerning prevention of unwanted pregnancies.
- List and describe 5 birth control methods

In this unit, the topic of birth control will be addressed. Many factors affect the complexity of decisions concerning prevention of unwanted pregnancies. Some people view all birth control methods other than natural methods as wrong. These wishes should be respected as well as the decision to use artificial contraceptives. However, a program of education or training in sexuality to individuals who are or who may become sexually active must include a frank, factual presentation of the possibility of pregnancy and all the ramifications of that choice.

When making decisions about which method of contraceptive is most appropriate, two of the most important factors to consider are the potential risk and irreversibility of each alternative.

Risk includes considerations about potential consequences of not using a birth control method when an individual is sexually active. It also involves possible side effects, disadvantages, health risks, and other precautionary factors.

Irreversibility is another aspect in decision-making. A decision on birth control is irreversible (that is, impossible to reverse) when it basically cannot be changed or undone, as when a sterilization procedure is carried out. Irreversible birth control methods do not provide the option to change one's mind or to use a different approach later. The person will never be able to become pregnant after using an irreversible method.

When someone decides to become sterilized, the results will, at best, be very difficult to reverse. Although medical technology is developing that can reverse some sterilization procedures, a reversal of sterilization is definitely an exceptional circumstance. That is why a guardian cannot make that decision for their ward without a court order. On the other hand, an individual might decide to use contraceptives whose results are easily reversible (except in unusual cases), such as birth control pills, a diaphragm, spermicides, or an intrauterine device (IUD). Unlike sterilization, these methods are not permanent. Individual needs and considerations must be made when planning with regard to birth control, as with all aspects of life.

Although opinions vary regarding methods of contraception for people with developmental disabilities, physicians often recommend the pill, Norplant, Depo-Provera injections and, in some cases, sterilization. Other methods of birth control tend to be too complicated for reliable use by individuals from this population, and the percentage of failure is high, even under
optimum circumstances. Individual needs and abilities must be considered. Use of condoms is also taught to reduce the risk of sexually transmitted diseases.

Selecting the best birth control method is a decision that is made by the individual with the support of their team and their physician. It is not the job of the direct support staff to make this decision for anyone. However, direct support staff need to understand the range of choices available and be able to explain the risks and benefits of types of birth control that may be appropriate for a particular individual. Staff who are available and work directly with the person will provide support to help ensure the person is using the method correctly and assist the person in noting side effects.

On the following pages, a listing of birth control information is provided including these methods:

- a. Natural (fertility awareness)
- b. Barrier (Condoms, contraceptive cream or jelly, cervical cap)
- c. Hormonal (Norplant, Pill, Depo-Provera)
- d. Mechanical (IUD)
- e. Surgical (Sterilization)

The headings of description, effectiveness, advantages, possible disadvantages, possible health risks, and caution for user are intended to assist staff members and individuals, as important decisions are made in this area. All of the main methods currently available have been included because it may be helpful to have this information available.

**BIRTH CONTROL INFORMATION**

**Male Condom, Latex/Polyurethane**

- FDA Approval Date: Latex: Use started before pre-market approval was required. Polyurethane: cleared in 1989; available starting 1995.
- Description: A sheath placed over the erect penis blocking the passage of sperm.
- Failure Rate (number of pregnancies expected per 100 women per year): 11 \((a, b)\)
- Some Risks (serious medical risks from contraceptives are rare): Irritation and allergic reactions (less likely with polyurethane)
- Protection from Sexually Transmitted Diseases (STDs): Except for abstinence, latex condoms are the best protection against STDs, including herpes and AIDS.
- Convenience: Applied immediately before intercourse; used only once and discarded.
- Polyurethane condoms are available for those with latex sensitivity.
- Availability: Nonprescription

**Female Condom**

- FDA Approval Date: 1993
- Description: A lubricated polyurethane sheath shaped similarly to the male condom. The closed end has a flexible ring that is inserted into the vagina.

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Failure Rate (number of pregnancies expected per 100 women per year): 21
Some Risks (serious medical risks from contraceptives are rare): Irritation and allergic reactions
Protection from Sexually Transmitted Diseases (STDs): May give some STD protection; not as effective as latex condom
Convenience: Applied immediately before intercourse; used only once and discarded.
Availability: Nonprescription

Diaphragm with Spermicide
FDA Approval Date: Use started before premarket approval was required.
Description: A dome-shaped rubber disk with a flexible rim that covers the cervix so that sperm cannot reach the uterus. A spermicide is applied to the diaphragm before insertion.
Failure Rate (number of pregnancies expected per 100 women per year): 17 (b, d, e)
Some Risks (serious medical risks from contraceptives are rare): Irritation and allergic reactions, urinary tract infection. (c) Risk of Toxic Shock Syndrome, a rare but serious infection, when kept in place longer than recommended.
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: Inserted before intercourse and left in place at least six hours after; can be left in place for 24 hours, with additional spermicide for repeated intercourse.
Availability: Prescription

Cervical Cap with Spermicide
FDA Approval Date: 1988
Description: A soft rubber cup with a round rim, which fits snugly around the cervix.
Failure Rate (number of pregnancies expected per 100 women per year): 17 (b, d, e)
Some Risks (serious medical risks from contraceptives are rare): Irritation and allergic reactions, abnormal Pap test. (c) Risk of Toxic Shock Syndrome, a rare but serious infection, when kept in place longer than recommended.
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: May be difficult to insert; can remain in place for 48 hours without reapplying spermicide for repeated intercourse.
Availability: Prescription

Spermicide Alone
FDA Approval Date: Use started before premarket approval was required. Starting November 2002, only one active ingredient will be allowed.
Description: A foam, cream, jelly, film, suppository, or tablet that contains nonoxynol-9, a sperm-killing chemical
Failure Rate (number of pregnancies expected per 100 women per year): 20-50 (studies have shown varying Failure Rates)
Some Risks: (serious medical risks from contraceptives are rare): Irritation and allergic reactions, urinary tract infections (c)
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: Instructions vary; check labeling. Inserted between 5 and 90 minutes before intercourse and usually left in place at least six to eight hours after.
Availability: Nonprescription
Oral Contraceptives--combined pill
FDA Approval Date: First in 1960; most recent in 2000
Description: A pill that suppresses ovulation by the combined actions of the hormones estrogen and progestin.
Failure Rate (number of pregnancies expected per 100 women per year): 1
Some Risks (serious medical risks from contraceptives are rare): Dizziness; nausea; changes in menstruation, mood, and weight; rarely, cardiovascular disease, including high blood pressure, blood clots, heart attack, and strokes
Protection from Sexually Transmitted Diseases (STDs): None, except some protection against pelvic inflammatory disease
Convenience: Must be taken on daily schedule, regardless of frequency of intercourse.
Availability: Prescription

Oral Contraceptives--progestin-only minipill
FDA Approval Date: 1973
Description: A pill containing only the hormone progestin that reduces and thickens cervical mucus to prevent the sperm from reaching the egg.
Failure Rate (number of pregnancies expected per 100 women per year): 2
Some Risks (serious medical risks from contraceptives are rare): Irregular bleeding, weight gain, breast tenderness, less protection against ectopic pregnancy
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: Must be taken on daily schedule, regardless of frequency of intercourse.
Availability: Prescription

Patch (Ortho Evra)
FDA Approval Date: 2001
Description: Skin patch worn on the lower abdomen, buttocks, or upper body that releases the hormones progestin and estrogen into the bloodstream.
Failure Rate (number of pregnancies expected per 100 women per year): 1 (Appears to be less effective in women weighing more than 198 pounds.)
Some Risks (serious medical risks from contraceptives are rare): Similar to oral contraceptives--combined pill
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: New patch is applied once a week for three weeks. Patch is not worn during the fourth week, and woman has a menstrual period.
Availability: Prescription

Vaginal Contraceptive Ring (NuvaRing)
FDA Approval Date: 2001
Description: A flexible ring about 2 inches in diameter that is inserted into the vagina and releases the hormones progestin and estrogen.
Failure Rate (number of pregnancies expected per 100 women per year): 1
Some Risks (serious medical risks from contraceptives are rare): Vaginal discharge, vaginitis, irritation. Similar to oral contraceptives--combined pill
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: Inserted by the woman; remains in the vagina for 3 weeks, then is removed
for 1 week. If ring is expelled and remains out for more than 3 hours, another birth control method must be used until ring has been used continuously for 7 days.
Availability: Prescription

Post-Coital Contraceptives (Preven and Plan B)
FDA Approval Date: 1998-1999
Description: Pills containing either progestin alone or progestin plus estrogen
Failure Rate (number of pregnancies expected per 100 women per year): Almost 80 percent reduction in risk of pregnancy for a single act of unprotected sex
Some Risks (serious medical risks from contraceptives are rare): Nausea, vomiting, abdominal pain, fatigue, headache
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: Must be taken within 72 hours of having unprotected intercourse.
Availability: Prescription

Injection (Depo-Provera)
FDA Approval Date: 1992
Description: An injectable progestin that inhibits ovulation, prevents sperm from reaching the egg, and prevents the fertilized egg from implanting in the uterus.
Failure Rate (number of pregnancies expected per 100 women per year): less than 1
Some Risks (serious medical risks from contraceptives are rare): Irregular bleeding, weight gain, breast tenderness, headaches
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: One injection every three months.
Availability: Prescription

Injection (Lunelle)
FDA Approval Date: 2000
Description: An injectable form of progestin and estrogen
Failure Rate (number of pregnancies expected per 100 women per year): less than 1
Some Risks (serious medical risks from contraceptives are rare): Changes in menstrual cycle, weight gain. Similar to oral contraceptives--combined.
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: Injection given once a month.
Availability: Prescription

Implant (Norplant)
FDA Approval Date: 1990
Description: Six matchstick-sized rubber rods that are surgically implanted under the skin of the upper arm, where they steadily release the contraceptive steroid levonorgestrel.
Failure Rate: (number of pregnancies expected per 100 women per year): less than 1
Some Risks: (serious medical risks from contraceptives are rare): Irregular bleeding, weight gain, breast tenderness, headaches, difficulty in removal
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: Implanted by health-care provider in minor outpatient surgical procedure; effective for up to five years.
Availability: Prescription. In July 2002, Norplant's manufacturer announced that it will no longer distribute the Norplant system. Women using the system should contact their doctors about what their contraceptive options will be after the five-year expiration date of their Norplant systems.

**IUD (Intrauterine Device)**

FDA Approval Date: 1976

**Description:** A T-shaped device inserted into the uterus by a health professional.

**Failure Rate:** (number of pregnancies expected per 100 women per year): less than 1

**Some Risks:** (serious medical risks from contraceptives are rare): Cramps, bleeding, pelvic inflammatory disease, infertility, perforation of uterus

**Protection from Sexually Transmitted Diseases (STDs):** None

**Convenience:** After insertion by physician, can remain in place for up to one or 10 years, depending on type.

**Availability:** Prescription

**Periodic Abstinence**

FDA Approval Date: N/A

**Description:** To deliberately refrain from having sexual intercourse during times when pregnancy is more likely.

**Failure Rate:** (number of pregnancies expected per 100 women per year): 20

**Some Risks:** (serious medical risks from contraceptives are rare): None

**Protection from Sexually Transmitted Diseases (STDs):** None

**Convenience:** Requires frequent monitoring of body functions (for example, body temperature for one method).

**Availability:** Instructions from health-care provider

**Surgical Sterilization--female**

FDA Approval Date: N/A

**Description:** The woman's fallopian tubes are blocked so the egg and sperm can't meet in the fallopian tube, preventing conception.

**Failure Rate:** (number of pregnancies expected per 100 women per year): less than 1

**Some Risks:** (serious medical risks from contraceptives are rare): Pain, bleeding, infection, other post-surgical complications

**Protection from Sexually Transmitted Diseases (STDs):** None

**Convenience:** One-time surgical procedure.

**Availability:** Surgery
Surgical Sterilization--male

FDA Approval Date: N/A
Description: Sealing, tying, or cutting a man's vas deferens so that the sperm can't travel from the testicles to the penis. (g)
Failure Rate (number of pregnancies expected per 100 women per year): less than 1
Some Risks (serious medical risks from contraceptives are rare): Pain, bleeding, infection, other minor postsurgical complications
Protection from Sexually Transmitted Diseases (STDs): None
Convenience: One-time surgical procedure.
Availability: Surgery

(a) Projected from six-month study and adjusted for use of emergency contraception.
(b) If spermicides are used with barrier methods, be sure that the spermicide is compatible with the condom or diaphragm (won't cause it to weaken or break). Oil-based lubricants (such as petroleum jelly or baby oil) will cause latex to weaken and should not be used with these methods.
(c) Spermicides should not be used during pregnancy.
(d) Medications for vaginal yeast infections may decrease effectiveness of spermicides.
(e) Less effective for women who have had a baby because the birth process stretches the vagina and cervix, making it more difficult to achieve a proper fit.
(f) First approval date of currently marketed IUDs. Some IUDs were sold before premarket approval was required. Those products are no longer on the market.
(g) A contraceptive option for people who don't want children. Considered permanent because reversal is typically unsuccessful.

Notes On "Other Methods"

You may hear about other, "new" methods of birth control. Be aware that there are many experimental methods in different stages of research and evaluation. Be sure principles of informed consent are followed before any of these methods are used. If a method is experimental, the consumer should be so informed. The fact that methods are available is no guarantee of their effectiveness or safety.

Curriculum Resources and Information Appropriate to Topic

Due to the evolution of information on this topic, probably the best way to find resources would be at websites:

Websites

Kaiser Family Foundation’s site: http://www.itsyoursexlife.org/
Planned Parenthood site: http://www.plannedparenthood.org/bc/
Columbia University’s general health site: http://www.goaskalice.columbia.edu/
Unit 8: Feedback Exercise

1. What are the five basic categories of birth control?

2. Rights are accompanied by_________________.

3. Give two factors that affect decision-making with regard to prevention of unwanted pregnancies. Explain.
UNIT 9: Putting It All Together

Objectives:

After completing this unit staff members will be able to:

• Identify possible solutions to real-life situations.

Real - Life Situations

Below is a list of possible situations which could cause concern for staff who provide supports for individuals with developmental disabilities. Taking into account your personal comfort zones and your facility's policy, identify 1) a possible solution at an administration level and 2) what you can do to improve the situation now.

_____ 1. Susan accepted a ride from a man she doesn't know.
_____ 2. A man with developmental disabilities wants to be alone with his girlfriend.
_____ 3. Two men who live in the group home are kissing in the garage.
_____ 4. A woman receiving services thinks she is pregnant.
_____ 5. A man with development disability isn't interested in sex.
_____ 6. You think one of the men receiving services is masturbating in the bathroom at his home.
_____ 7. Talking about sex makes you feel uncomfortable.
_____ 8. A woman with developmental disabilities wants to know what a penis is.
_____ 9. Sarah's parents don't want her to date men even though she is an adult.
_____ 10. You think an individual with intellectual disabilities is being sexually exploited by a roommate.

Discussion:

The team process allows staff members to gain insight and direction. Let us examine them in light of the limited information available. In "real life" the individual needs and other factors must be taken into account. In all cases, staff should be sensitive to the needs of the individual (couple) and foster dignity and respect.

Question 1: Assuming the woman is home safe now, the situation must be reported. She
needs education on the dangers involved and alternative choices.

Question 2: Be sensitive to the needs of the couple. The team should review and discuss training needs (i.e. birth control, prevention of sexually transmitted diseases, relationships, and rights).

Question 3: Write an incident report and follow proper channels in your agency.

Question 4: The first step must be to examine what makes this woman think she is pregnant. Does she understand how it happens? Does she understand the symptoms? Does she know what "pregnant" means? Then go on from there according to your facility's policies.

Question 5: People vary with regard to sexual interests and have the right to decide for themselves.

Question 6: Is it interrupting his training or other responsibilities? If it is, your actions should be the same as if he were taking a long bath. Refer to your supervisor and agency policy for direction.

Question 7: Refer questions to someone more comfortable, if needed. You can receive sexuality training to educate yourself and perhaps learn to become more comfortable.

Question 8: Tell her. If you are uncomfortable with this, refer her to someone else. Use pictures, etc.

Question 9: This is a matter for the interdisciplinary team. It may be necessary to involve an advocate.

Question 10: Report this to the proper people according to your agency's abuse and neglect policy immediately. Talk to your supervisor.
Feedback Answers

Unit 1:

5. Consider the following topics for social/sexual instruction. Pick at least three of the topics and identify individuals whom you support who may benefit from informal or formal teaching on this topic. Explain your answers
   - Body parts, including penis and vagina
   - Changes that occur during puberty
   - Birth control and the implications of parenting
   - Discrimination of “public” versus “private” behavior
   - Inappropriate sexual behavior (imposing a person’s sexual desires on someone who is not willing, sexual contact with a minor, public sexual behavior)
   - Expressing affection, love and intimacy
   - Sexual rights
   - Sexually transmitted diseases

   Answers will vary.

6. List at least two suggestions presented in this unit for including social/sexual education in day-to-day interactions with individuals with developmental disabilities?
   - Be an approachable person
   - Be ready to supply necessary training at developmental stages

7. What are five factors that could influence an individual’s understanding about sexuality?
   - Difficulty in learning
   - Physical and social overprotection
   - Segregated living situations
   - Group living situations
   - Supported living situations

8. Describe the role of staff in supporting people to achieve the personal outcome measure, “People Have Intimate Relationships”.
   - Provide assistance for people to learn about relationships
   - Assist the person in making choices
   - Support people in arranging and accessing opportunities for relationships.

Unit 2

5. Explain what a social support network is.

   Social support network includes the whole range of relationships people develop. All types and degrees of relationships are included in this network, including short to long term; impersonal to intimate; negative to positive.

6. Define the word "relationship".
A relationship, means any kind of connection (especially a close connection) that one has with someone else.

7. Describe the various qualities of a close, positive relationship.

In close, positive relationships:

e. Both people trust each other.

f. They can be honest with one another and be themselves.

g. The relationship is not a constant drain on either person’s energy. Both people in the relationship feel good about themselves.

h. Neither person is in charge all of the time or takes orders all of the time. There's a sharing of responsibility and effort.

i. Even though the people involved generally enjoy each other's company, they don't have to be together all of the time.

j. In addition to their shared interests, each person has some interests that are different from the other person’s.

k. There are more "ups" than "downs" in the relationship. If most feelings are jealousy, resentment, misery, or anger, it's recommended that a person take another look at that relationship to see if it's a healthy one.

l. One feels like a whole person whether they're with or apart from the other person. They don't look to the other person to "make them whole."

8. Name at least three uses of relationship mapping

Assessing, teaching, planning, sustaining or building relationships

Unit 3

1. Why is it important to explore our own personal values?

The duty of staff is to share factual, fair information, and socially acceptable behaviors, not values. If you cannot separate the two, don't address the issue, refer it to someone who can.

2. Name 3 things that can be considered “sexuality.”

Sexuality is made up of many components; physical, cosmetic, dress, feeling, relationships, self image, values, touch, etc. Sexual acts are only one part of sexuality.

3. Why should we carefully consider sexuality questions by people with cognitive disabilities?

To make sure you understand the true inquiry behind the words.
Unit 4

5. Give the five basic steps to aid in good judgment and objectivity, outlined in this unit.
   
a. Be objective
b. Consider the situation
c. Preserve the individual's dignity
d. Teach the appropriate behavior
e. Report the behavior according to your agency's guidelines

6. Why is it important to make complete, accurate, and objective reports regarding sexual behaviors.

   Complete, accurate, and objective reporting of sexual behavior may promote medical and psychological well-being of the individual and enhance good team decision making.

7. The value of an effective policy on sexual behavior is consistency.

8. Name 3 rights of people in the area of sexuality.
   
   • The right to make personal choices about sexual values, preferences, and behavior
   • The right to be given accurate information about sex education in an understandable way
   • The right to sexual expression
   • The right to privacy
   • The right to have a "significant other" or to marry if the person chooses
   • The right to choose parenthood; this also requires the right to be given information about birth control options, and to choose or refuse contraception and/or sterilization
   • The right to receive services needed; counseling, legal aid, social, and recreation services with the opposite sex

Unit 5

1. What are the three general headings for training outlined in this unit?
   
a. Understanding and accepting self
b. Building relationships for better interactions with others
c. Accepting group mores for adjustment into society

2. Like all other training, goals in the area of sex education should be individualized.

3. Give at least four dangers of not providing individual sex education.
   
   • Experiencing doubt and guilt about the body, feelings, and normal sexual growth
• Embarrassment for the person
• Potential sexual exploitation and abuse
• Unacceptable social/sexual behavior, perhaps even resulting in legal consequences
• Possible ridicule and avoidance by society
• Unplanned pregnancy
• Sexually transmitted disease

4. What is the primary desire of all people, any person?

When asked, the primary desire of people, any person, is to have a significant life partner with whom to share their lives.

5. Why does the module suggest that staff use technical language when reporting and teaching but be familiar with street language and common language??

You may need to ‘talk the talk’ that others use in order to build rapport and trust with them. If you correct a person’s language too soon you may miss some valuable information they are preparing to share.

Unit 6

1. Give at least three reasons why individuals with disabilities tend to be more vulnerable to sexual abuse in our society.

   a. Offenders may think it is "safer" to abuse someone with disabilities
   b. Individuals with disabilities do not receive the same information that peers of the same age groups receive about sexual abuse
   c. Individuals with disabilities are often dependent upon professionals and others
   d. Sometimes individuals with disabilities request or are offered assistance from strangers who may take advantage of the situation and become abusive

2. Three common feelings or reactions to sexual assault are fear-anxiety reactions, guilt-self-blame-embarrassment, and anger.

3. It has been estimated that more than 2/3 of perpetrators of sexual abuse were previously known to the victim with a developmental disability.

4. Obtaining knowledge about sexual abuse is the first step toward it's prevention.

5. Because sexual abuse frequently goes unreported, it is important to be aware of possible physical and behavioral indicators that it may have occurred. Name at least five potential indicators.

   a. Difficulty in walking or sitting
   b. Torn, stained, or bloody underclothing
   c. Pain or itching in the genital areas
d. Bruises or bleeding in genital anal areas  
e. Venereal disease  
f. Pregnancy  
g. Difficulty sleeping, or sudden and frequent nightmares/sleep disturbances  
h. Avoidance of a previously trusted and well-liked person, especially anyone in a position of authority  
i. Unexplained stomachaches or change in eating habits  
j. Fear of being left alone, or the unusual desire to be alone (withdrawal)  
k. Change in leisure habits, or reluctance to join in previously enjoyed recreational activities  
l. Delinquency or running away  
m. Bizarre, sophisticated, or unusual sexual behavior or knowledge  
n. Hypochondria  
o. Refusal to undress, to bathe, or to be bathed  
p. Depression  
q. Self mutilations  
r. Excessive masturbation  
s. Poor self-image  
6. Describe staff guidelines for sexual abuse prevention training:  
   i. Be aware of their personal comfort level in dealing with sexual abuse.  
   j. Utilize a person from a sexual abuse center or other community agency as a resource.  
   k. Offer sexual abuse prevention training in the most appropriate setting.  
   l. Modify the curriculum to meet the needs of individuals. If working with people with multiple disabilities, or in a situation where a variety of disabilities are represented, it may be best to select portions to offer based on team recommendations. Flexibility is the key to meeting individual needs.  
   m. Do research on existing community resources beforehand. Obtain names and telephone numbers of contact persons.  
   n. Deal with embarrassment early in the discussion.  
   o. Stress that anyone is vulnerable to sexual abuse.  
   p. Think about how you will talk to a person who discloses sexual abuse.  
7. What are the basic topics in a sexual abuse prevention curriculum?  
   • Vocabulary - learning words used in discussing the body as well as sexual abuse.  
   • Touch - identifying different types of touching and communicating feelings about various touches  
   • Facts About Sexual Abuse - learning factual information about sexual abuse.  
   • Information about situations where sexual abuse could occur, including strangers, acquaintances, and family members. Emphasize that certain behaviors increase the risk of sexual abuse.  
   • Basic information about reporting sexual abuse, the medical examination (if required), prosecution, community resource people, and people identified who can be told about the sexual abuse.
• How victims feel during, directly after, and days, weeks or even years after the abuse.
• Prevention of abuse by both stranger and acquaintances. Discussion should be focused on avoidance and telling rather than self-defense.
• Practicing assertive responses.

8. What should staff do, when a person receiving services discloses sexual abuse?

   Believe the person.
   Let them point and use slang terms to describe what has happened.
   Acknowledge the importance of talking about the abuse and getting help.
   Remain neutral in your reaction.
   Avoid judging or asking "why" questions.
   Empower the victim by affirming and supporting her/his feelings, listening to her/his concerns, fears and needs and educating her/him about available resources.
   Refer according to agency's policies and procedures.

**Unit 7**

1. STD stands for **Sexually Transmitted Disease**.

2. An STD is spread by sexual intercourse, close body contact involving the genitals, mouth, and/or rectum.

3. Sexually transmitted diseases can be **prevented** by responsible sexual conduct.

4. What is the most effective method to prevent transmission of sexually transmitted diseases?

   Abstinence

5. List other ways to prevent the transmission of STDs.
   Exclusive relationships with partners who do not have STDs.
   Condoms
   Intimacy other than sexual intercourse, close body contact involving genitals, mouth, and/or rectum.

**Unit 8**

1. What are the five basic categories of birth control?
   a. Natural
   b. Barrier
   c. Hormonal
   d. Mechanical
e. Surgical

2. Rights are accompanied by responsibilities.

3. Give two factors that affect decision-making with regard to prevention of unwanted pregnancies. Explain.

   Risk and irreversibility (see unit for explanation of each).