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Aspects of Sexuality

INTRODUCTION

Sexuality is a key facet of daily life, but not one that people always feel comfortable discussing. This likely has to do with the prevailing perceptions of what sexuality is, namely physical intimacy. However, sexuality is a much broader category of feelings, thoughts, and ways of seeing others and the world. It influences us in all aspects of our lives, sometimes without us ever realizing it. For individuals with I/DD, this topic is especially important because it is often overlooked, which can impact their relationships with others, their views of themselves, and even their safety.

This edition of the *HCQU CARES* newsletter presents information for caregivers on the different aspects of sexuality that impact the lives of individuals with I/DD and ways to educate them about it. This includes articles that cover the importance of sexuality education and what constitutes a sexually healthy agency approach to the subject; definitions of terms that people may be curious about or need to know to avoid or report possible abuse; ideas for how to recognize a healthy versus an unhealthy relationship that caregivers can review with individuals; and ways to reduce the risk of sexual abuse for people with I/DD. With this information, both individuals and caregivers may find a new understanding for the importance of sexuality education and awareness in maintaining health and safety.



Sexuality Education and PEOPLE WITH I/DD

By: Erin Sass, Behavioral Health Clinical Educator

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Sexuality is more than sex, the act. Sexuality is about intimacy, connection, and belonging. It's about relationships – friendships and romantic. It's about how we feel about the gender we are, about others, and about ourselves. It's about sexual expression and behavior. It's a total of who we are, what we believe, what we feel, and how we respond. – Katherine McLaughlin, Elevatus Training

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Talking about sexuality with another person isn't always easy and can make caregivers, parents, and people with I/DD uncomfortable. Some people are overwhelmed by the thought of it or don't know where to begin. Some people believe that people with disabilities don't need sexuality information. Others think that sexuality is only about the act of having sex, and if they teach others about sexuality, they'll want to have sex all the time. It is easy to see how this topic can go unaddressed. These are understandable concerns that caregivers and parents might have on behalf of the people they are supporting.

As sexuality educator Katherine McLaughlin has stated, "Even though the media may present a narrow view of who is considered sexual, we really are all sexual beings" (2003). Sexual beings aren't just models and celebrities that people see in the media; every person is a sexual being, including people with disabilities – they have thoughts, feelings, and concerns about sexuality, just like anyone else.

People with disabilities have expressed a need and desire to learn about sexuality. Some of the reasons that self-advocates have mentioned for wanting this information include:

- "So we can learn to have healthy relationships."
 - "So we can be safe!"
 - "So we aren't lonely!"
 - "Because we all have desires and needs and that's OK."
 - "So we are able to make informed choices."
 - "To help make relationships last."
 - "So we can pick the right person!"
 - "So we know our rights!"
- (Elevatus Training, 2018)

Information presented in movies, TV shows, and social media can be confusing, misleading, or simply incorrect when situations are not realistic and messages are unclear or not credible. Some people with disabilities might not be able to identify a situation as real or pretend. If an actor in a TV show played a man who has multiple girlfriends, lies to each of them, and is admired by his friends, most people would recognize this situation as unrealistic, based on their education and experience with regard to sexuality. A person with I/DD, however, might perceive the show as real and conclude that having more than one girlfriend or boyfriend is acceptable – even desirable. Furthermore, media tends to portray sexual experiences as always exciting or amazing, while real sexual experiences might or might not be. People with I/DD who receive such confusing messages might develop unrealistic expectations, or view themselves as undesirable because they aren't having the same experiences as the people in a show/movie. One thing that caregivers can do is to encourage individuals not to compare their experiences to what they see on television, because television is not real life.

Effective sexuality education presents medically accurate and factual information in a clear and concrete way. This approach encourages people with disabilities to scrutinize the information and messages received from unreliable sources. The information should be clear, concrete, and easy to understand and offer positive messages about oneself, sexuality, and relationships. Throughout their lives, people with I/DD tend to receive negative messages about sexuality – “You shouldn't talk about it”; “it's dirty and you'll get a disease”; or “it's only for people who are responsible and make good decisions”. Negative messages and scare tactics like these might prevent people with disabilities from getting the information they need to be sexually healthy and create a barrier to understanding their values, bodies, and safety.

Abuse awareness is another key facet of sexuality education for people with I/DD. People with disabilities are at greater risk for sexual abuse than people in the general population (Elevatus, 2003). This may stem from being expected to do or go along with what they are told, not having factual information on their bodies and privacy, or wanting to please others. Therefore, it is important to teach people with I/DD the proper names are for body parts, to recognize healthy versus unhealthy relationships, and to say “No” to unwanted touch.

Although sexuality education is important from a health and safety standpoint, there are caregivers who find helping people with I/DD gain access to information about sexuality difficult. Some are motivated by a desire to protect individuals; they might believe that acknowledging sexuality with an individual causes harm by making the individual uncomfortable. Others might be afraid of ‘stirring up’ sexual feelings; they might think talking about sexuality will introduce thoughts and fantasies to the individual that did not exist before. Still others might be uncomfortable with the subject; they might convince themselves that avoiding the topic will prevent it from ever becoming a part of the individual's life. What these caregivers need to know is that the absence of reliable information and/or the opportunity to talk about it with a trusted person has detrimental effects on the person's quality of life. Without a fact-based understanding of sexuality, an individual might believe that it is okay to touch others inappropriately because it ‘feels good’, or that their sexual feelings for others are always reciprocated. With an informed awareness of the barriers and methods for overcoming them, caregivers become better prepared to discuss sexuality with individuals to enable individuals to enjoy a better quality of life.

For more information or training on this topic, visit the KEPRO HCQU website at www.hcqu.kepro.com.

References:

Elevatus Training: GULP! Talking with Your Kids About Sexuality Newsletter, Volume 4, Number 1, May 2003

IS YOUR AGENCY SEXUALLY HEALTHY?

Below is a list of the qualities of a 'sexually healthy' agency. Use this list to explore whether your agency is prepared to promote good sexual health, or if additional resources are required. (This list is not all-inclusive; it is intended to offer provider agencies positive perceptions of sexuality to encourage healthy communication with individuals about sexuality.)

- All people with disabilities are viewed as sexual beings who have desires and needs.
- If someone wants a sexual relationship or has questions about sexuality, they are given the opportunity to ask and help to find the answers they need.
- People with disabilities and caregivers see sexual expressions as a normal and healthy part of life.
- Caregivers don't react; they respond in a positive way.
- Messages given are sex positive and demonstrate an openness to the topic.
- People with disabilities have access to sex positive, age appropriate sexuality education that is not fear based.
- All people are accepted for who they are whether it be gay, straight, bisexual, asexual, pansexual, or transgender.
- Caregivers who support people with disabilities aren't afraid to address the topic.
- Caregivers have access to training on how to address the subject.
- Staff understand that they should not impose their values on a person with a disability.
- When sexuality comes up, people can talk openly and respectfully about the topic.

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TIPS FOR TALKING ABOUT SEXUALITY

What does it take to have a good and successful conversation about sexuality? Here are a few tips that can point you in the right direction.

Caregivers/parents might have to initiate the conversation. This can be done by gently raising the topic with the person. Perhaps the simplest way to do this is to use examples from daily life – for instance, talking about the relationship of a famous couple. If the person has been showing interest in sexual topics, consider using relevant observations to initiate a conversation. For example, you may say, "Now that you are showing interest in intimate relationships, do you have any questions about your body, or different kinds of feelings you may be having?" Some people have questions about sexuality, but either do not know how or are afraid to ask.

Give age appropriate information. When talking about sexuality, select information appropriate to the person's biological age, not his or her "cognitive" age, so the person receives information that is right for their bodies. For example, when talking with a 12 year old who has a cognitive age of 5 and is experiencing puberty, offer information about changes that occur in the body of a 12-year-old. Consider the person's cognitive age

when deciding on the language used to communicate the information, so the person is able to understand it. Check with the person frequently to confirm the information is understood.

Take advantage of teachable moments. Use everyday situations to start a conversation about sexuality and relationships. For instance, if you and the person notice a couple holding hands while walking in the community, ask the person, “What do you think about that?” to start a conversation about relationships that encourages the person to ask questions. Make sure the moment is applicable to what the person needs in terms of sharing information and understanding concepts. Allow time between conversations about sexuality to avoid overwhelming the person or making them feel uncomfortable.

Keep answers simple. Less is more!

Be patient. Sexuality and relationship concepts might need discussed multiple times. Individuals might ask the same questions over and over to help them understand and retain the information. Keep information concrete – use pictures, sketches, anatomically correct dolls, or videos.

Try to not react. If the person asks a question or makes a statement that is shocking, try to remain calm and neutral. Restate your understanding of the question or statement and offer an appropriate response. Monitor your body language – try to avoid crossing your arms or legs, turning or backing away from the person, and displaying shocked/surprised facial expressions; move your hands to emphasize points in a friendly manner; and maintain an open, approachable posture. This can help the individual feel at ease and help you feel more comfortable, as well.

Use a book on sexuality to explain specific topics. A book that is factual and intended as a teaching tool can take some of the discomfort out of the conversation. Don't be afraid to talk about topics that are embarrassing. A great way to do this is to use tactful humor that the person will understand and laugh with them. Laughing together can take some of the embarrassment out of the conversation. Try to look at the book with the person and use it to guide open and honest discussion about the person's questions.

Don't expect to know the answer to every question. If you do not know an answer, say “I don't know,” or “I have to think about that.” Then, look up the answer and communicate the answer to the person later. You may choose to refuse to answer personal questions. Model appropriate boundaries by explaining that personal information is private and that there are limits to what people want to share. Talk about times when it is acceptable to talk about sexuality (e.g., with a friend or trusted professional who is comfortable talking about it with them). Again, some people can be offended or made uncomfortable concerning this topic – others may see the individual as a target for abuse.

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Elevatus Training: GULP! Talking with Your Kids About Sexuality Newsletter, Volume 4, Number 1, May 2003

SEXUALITY TERMINOLOGY

There are many terms used to describe people, their sexual behaviors, their sexual identities and orientations, and interests. Sometimes these terms are used incorrectly. The following are some terms and definitions that might provide some clarity.

Sex:

1. A label — male or female — assigned by a doctor at birth based on the genitals and chromosomes present at birth. A baby's sex is indicated on the birth certificate.

2. The act of engaging in sexual behavior with another person.

Sexual orientation: refers to the gender(s) to which a person is attracted and desires relationships. Sexual orientations include gay, lesbian, straight, bisexual, and asexual.

Sexual health: refers to enjoying emotional, physical, and social well-being with regard to one's sexuality, including free and responsible sexual expression that enriches one's life.

Sexual preference: People, activities, or other things that a person likes, sexually.

Gender is much more complex:

1. A social and legal status (male or female)
2. A set of expectations from society about behaviors, characteristics, and thoughts. Instead of being about body parts, gender is about how one is expected to act based on their sex. Every culture has standards about how people are expected to behave based on gender.

Gender identity: How a person feels inside and perceives their gender based on feelings that begin very early in life. A person's gender identity does not always match the sex assigned at birth.

Gender expression: How a person chooses to display gender on the outside, through clothes, hairstyles, or other markers chosen. A person's gender expression does not have to match their gender identity. For example, a person who likes to wear masculine clothes may still identify as a woman.

Gender binary: The idea that there are only 2 genders – male and female – which are mutually exclusive and different.

Gender fluidity: A sense that one's gender identity or expression is not permanent; it can change over time or even from day to day. For some people, gender fluid is a gender identity. A gender fluid person might feel male on some days, female on others, both male and female, or neither.

Transgender: An umbrella term used to describe people whose gender identity and expression differ from what is usually associated with their birth sex or assigned sex.

Transsexual: A person whose gender identity does not match their biological sex.

Homosexual (lesbian/gay): Being attracted to people of the same gender.

Bisexual: Being sexually attracted to both men and women; sometimes used to describe people who are sexually attracted to people of all genders, including non-binary genders.

Pansexual: Having sexual or romantic attraction to people of all genders.

Cisgender: Refers to those who identify as the sex they were assigned at birth.

Asexuality: Sexual orientation or identity associated with experiencing no sexual attraction for anyone.

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Healthy Relationships

A KEY COMPONENT OF SEXUALITY

By: Brian J. Leech, MS

Understanding relationships is fundamental to understanding sexuality and its importance. People are drawn together by a desire to belong to a group, to be valued, to experience positive feelings, and to feel safe. People in healthy relationships tend to report feeling happier and having a more purposeful and enjoyable life. In fact, research has found that close relationships are better predictors of happiness than social status or income and can help prevent physical and cognitive health decline throughout one's life (Mineo, 2017). However, social isolation, abuse, trauma, health concerns, stigma, and a lack of education and experience about sexuality and healthy relationships can prevent people with intellectual and/or developmental disabilities from having the same opportunities to experience healthy relationships as people without I/DD (Alexandra, Angela, & Ali, 2018).

People in healthy relationships feel respected and included. Healthy relationships increase a person's protective factors to help reduce the risk for abuse. Protective factors include:

- Ability to communicate feelings and expectations
- Ability to work through complex social situations
- Understanding social behaviors such as helping, honesty, and listening
- Seeking out a trustworthy person, if needed
- Having social supports to prevent isolation (KEPRO HCQU, 2019)

Caregivers can help support people with I/DD to experience healthy relationships. Ideas for doing so are described below.

- Help the person develop the skills needed to develop and maintain a healthy relationship, such as:
 - Actively listening to the other person (e.g., being interested in what is said, giving the person one's full attention)

- Using open and friendly body language (e.g., arms relaxed at sides, face the other person, nod or say “go on” or “tell me more” to encourage conversation).
- Respecting personal space by staying at least two arm lengths from the person unless the person says it is okay to come closer.
- Sharing information about oneself when asked, but keeping the focus on the other (e.g., talking about your experience or opinion, then asking what the other person thinks).
- Teach the person about boundaries.
- Demonstrate and call attention to positive examples of healthy relationships.
- Seek out community activities for a person to meet people.
- Empower people to believe in themselves.
- Educate about healthy vs. unhealthy. The table below lists the characteristics of healthy and unhealthy relationships (KEPRO HCQU, 2019).

| SIGNS OF A HEALTHY RELATIONSHIP | SIGNS OF AN UNHEALTHY RELATIONSHIP |
|--|---|
| ✔ Person considers your feelings. | ✘ Person only thinks about what they feel or want. |
| ✔ Person respects your privacy & personal space. | ✘ Person always wants to know what you’re doing, where you’re going, who you’re with. |
| ✔ Person respects your family and friends. | ✘ Person doesn’t want you to be around your family or friends, says unkind things about them. |
| ✔ Person supports your decisions. | ✘ Person wants to make decisions for you, always tells you your decision is wrong. |
| ✔ You and the person treat each other with kindness and respect, enjoy being together. | ✘ You and the person seem to fight often, feel stress when together. |

In addition, caregivers can use the following questions to help individuals to evaluate their relationships.

- Is the relationship unbalanced? This might look like one person putting in much more effort to make the relationship work (e.g., calling the other frequently, trying to make plans with the other, and not seeing the same effort from that other person).
- Are there few shared interests? Does it appear that the people involved in the relationship don’t have much to talk about or that they enjoy doing together? If so, caregivers and individuals could explore different activities/events that might interest both of them.
- Does the individual really want to do an activity, or is the individual doing it because the other person wants to do it? In the context of the relationship, does one person seem to ‘go along’ with what the other wants? Does one person seem to make the plans or dictate how things will go? If so, this may not be a healthy relationship.

- Are necessary accommodations made to allow the individual to fully participate in the activity? Depending on the person's needs, caregivers might want to explore options that enable the individual to participate more fully in activities to help maintain the relationship. For instance, if a couple wants to go out for dinner, caregivers might provide transportation and/or assist the individuals to select a restaurant and budget for the outing.
- Is the presence of caregivers interfering with the development or health of the relationship? While it is important for caregivers to offer needed assistance, people need privacy to develop and maintain healthy relationships. Consider ways to ensure individuals have private time together to grow comfortable with each other.
- Is there enough structure to activities in which the individuals in a relationship are involved? While spending time together is key for a healthy relationship, a sense of structure is needed, too. For example, a 'date' typically involves a specific activity a couple does together (e.g., dinner, a movie, or a game of mini-golf) because the structure of the activity helps the couple to get to know each other and to enjoy their time together. Caregivers can encourage individuals to explore activities to do with another person as a way of providing structure and enjoyment to the time they spend together.
- Is an individual's attitude or behavior keeping others away? Sometimes people project attitudes or behaviors that prevent people from getting to know them. A variety of factors can cause this – past abuse and/or trauma, a lack of self-confidence, inexperience with relationships, or even challenges related to physical or mental health. If a person exhibits behaviors that make it difficult for him or her to have healthy relationships, consider seeking professional advice to ensure the individual is healthy and able to be in a relationship (adapted from Stengle, as cited in Pitonyak, 2005).

Visit the following links for more information on this topic.

www.aucd.org/docs/webinars/The%20Friendships%20&%20Dating%20Program.pdf

<https://www.loveisrespect.org/resources/download-materials/>

<https://www.plannedparenthood.org/learn/relationships>

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Reducing the Risk of **SEXUAL ABUSE FOR PEOPLE WITH I/DD**

By: Elizabeth Hobbs, Behavioral Health Clinical Educator

Sexual Abuse:

“The infliction of sexual contact upon a person by forcible compulsion.”

“Engaging in sexual contact with a person who is below a specified age or who is incapable of giving consent because of age or mental or physical incapacity.” (Merriam-Webster)

“... any sexual act or attempt to obtain a sexual act by violence or coercion, acts to traffic a person, or acts directed against a person’s sexuality, regardless of the relationship to the victim.” (WHO, 2002)

“... any sexual activity that occurs without consent.” (Psychology Today, 2020)

In 2012, members of the Spectrum Institute’s Disability and Abuse Project conducted the “2012 National Survey on Abuse of People with Disabilities,” the first national survey of its kind. The survey focused on incidents of, responses to, and attitudes about abuse or victimization of children and adults with disabilities (Baladerian et al, 2013). 41.6 % of people with disabilities who responded reported having been victims of sexual abuse. Furthermore, it was determined that the rate of sexual abuse varied greatly among victims depending on the type of disabilities they had (i.e., a mental health condition, I/DD, autism, and/or a mobility disability). In terms of those with I/DD specifically, 34.2% of the respondents reported having experienced some form of sexual abuse (Baladerian et al, 2013).

Sexual abuse can result in long-term consequences for people who have experienced it (Zollner, Fuchs, & Fegert, 2014). It is a concern for the person, his or her caregivers, and society, because it is widespread and impactful enough to create a public health issue (Zollner, Fuchs, & Fegert, 2014). Awareness of the possible signs and symptoms of sexual abuse is important both for the person and their caregivers; however, awareness is effective only in stopping the continuation of existing abuse. To reduce the risk of and prevent sexual abuse,

SIGNS OF SEXUAL ABUSE

Difficulty walking and/or sitting

Torn, stained, bloody clothing

Genital pain or itching

External genitalia bruising/bleeding/swelling

Frequent urinary tract infections

Dramatic changes in behavior

- Suddenly afraid
- Changes in hygiene
- Increase in challenging behaviors
- Runs away
- Fearful/avoidant of certain places

Sexually transmitted diseases (STDs)

Pregnancy

Inappropriate/sudden sexual knowledge

Nightmares

Bed wetting

Symptoms of depression or post-traumatic stress disorder (PTSD)

Suicidal thoughts

Medical and/or legal assistance should be sought as needed and as soon as possible, according to agency policies and procedures, state regulations, and/or the law. (RAAIN)

it is crucial for individuals and caregivers to have reliable and correct information (Zollner, Fuchs, & Fegert, 2014). Education and support are key in helping to prevent sexual abuse before it begins, but it must be available and useful for several groups – the individual, the organization or agency, the family/caregivers, and society as a whole (Zollner, Fuchs, & Fegert, 2014).

Successful prevention programs have these common traits:

- Make adults responsible for keeping minors safe
- Implement prevention measures on a short, frequent, regular basis
- Use appropriate language that is easily understandable and specific, yet comprehensive
- Ask if and what types of sexual education the individual has had
- Assume both men and women can be victims of sexual abuse
- Take into account issues specific to groups (i.e. gender, culture, religion)
- Implemented by a team representing both genders (Zollner, Fuchs, & Fegert, 2014).

WHAT DOES THIS MEAN FOR INDIVIDUALS WITH I/DD?

For all people, education that is adjusted to the person's specific needs, concerns, and knowledge has been shown to be effective. Before starting any kind of education, caregivers should obtain the person's consent to explore this topic with them. It is important for caregivers to learn what the person already knows/ understands about the topic and what questions the person has about it (McLaughlin, Topper, and Lindert, 2018). Information should be offered in short, frequent "lessons" on a regular basis and expressed in language that is clear, understandable, fact based, comprehensive, and specific to the person's needs. Information should be free of positive or negative judgment on the part of the presenter. The information selected should relate to the person's chronological age, not mental age. For example, someone experiencing puberty needs information specific about how the body changes and feelings they might experience, while someone in middle age needs information about maintaining sexual health (McLaughlin, Topper, and Lindert, 2018). Issues specific to the person (such as gender, gender identity, sexual orientation) should be considered, as well.

WHAT INFORMATION DOES A PERSON NEED?

Sexuality education includes a number of topics – body parts, sexual health, caring for the body, gender identity and expression, and prevention of sexually transmitted infections and unwanted pregnancy. However, comprehensive sexuality education is more than this. In fact, it could easily be described as “relationship education,” since it covers information focused on relationships with oneself and others (McLaughlin, 2020), including topics such as communication, friendships, moving from friends to sweethearts, and how to determine if relationships are healthy or abusive (McLaughlin, Topper, & Lindert, 2018). Sexuality education can also incorporate topics related to staying safe, such as public versus private spaces, wanted versus unwanted touch, internet and social media safety, and sound decision making (McLaughlin, Topper, & Lindert, 2018). Ultimately, the information is determined by the person and his or her needs.

ORGANIZATION SUPPORT FOR PEOPLE WITH I/DD

Effective sexuality education has organizational support in place to create an atmosphere that is conducive to learning (Zollner, Fuchs, & Fegert, 2014). A sexuality policy helps an organization establish a plan to address the needs of individuals in a safe and responsible manner and provides a consistent and unified approach for caregivers to follow when dealing with concerns, questions, or incidents related to sexuality.

To create a supportive atmosphere for learning, consider the following questions:

- Is there an agency policy on sexuality? If so, is everyone involved with the organization familiar with it? If not, what needs to happen to create one?
- What training and support is being offered to a person’s caregivers?
- Do individuals and caregivers have access to sexuality information that is clear, understandable, and fact-based?
- Is the information both comprehensive and specific to the person’s needs?
- Is support and training available to help caregivers provide this information in a judgement-free manner?
- What messages (subtle and otherwise) are caregivers being given regarding sexuality issues (McLaughlin, 2020)?

SOCIETAL LEVEL EDUCATION AND SUPPORTS

Societal level supports and education are practices incorporated by a society as a whole to offer support and education concerning sexual abuse awareness. These might include political goals, legal definitions and/or laws, social norms, expectations, and values. An awareness of these supports and norms in sexuality education can help to clarify what is appropriate versus what is abusive in terms of behavior (Zollner, Fuchs, & Fegert, 2014). The types of assistance and support offered (such as formal sex education in schools, programs for abuse victims), and the messages received from society regarding sexuality also fall under this category. Understanding societal supports, expectations, and norms is vital to sexuality education; they can help people avoid actions that lead to legal trouble and recognize the rights of others and themselves.

There are several facets to sexuality education and support. If you have questions about sexuality education, resources, or supports, please feel free to contact the KEPRO HCQU.

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