

the elephant

in the room

talking to your teen and young adult with a
disability about love, dating, safety, and
relationships

Produced by


The Arc
of South Carolina

In conjunction with


SOUTH CAROLINA
Developmental Disabilities Council



who

SHOULD READ THIS?

This guide was developed by The Arc of South Carolina for parents, caregivers, loved ones, and others who have children, teens, and young adults in their lives with intellectual and developmental disabilities. Intellectual and developmental disabilities can include Autism Spectrum Disorder, Down syndrome, cerebral palsy, Fragile X syndrome, shaken baby syndrome, fetal alcohol syndrome, and others. Individuals with ADHD and learning disabilities may also benefit from the resources provided.

what

IS IN HERE?

Love, sex, dating, boundaries, safety, and all of the topics in between could take a lifetime to adequately discuss—and we never stop learning! This guide is not intended to be a one-stop resource for all of your needs, but it will give you tools, suggestions, and activities to aid in having these often difficult conversations with loved ones. To be fair, it's *never* easy to have these conversations even with typically developing children, but those with disabilities face additional barriers that may make the task even more daunting.

In this resource:

- Developmentally appropriate activities and how to use them
- Tips for becoming more comfortable with having sensitive conversations
- Suggestions for starting conversations
- Additional resources for further research
- Facts & statistics

why

SHOULD I TALK ABOUT THIS?

Many parents assume that their child with a disability will never be interested in dating, relationships, or sex. This could not be further from the truth! Most people with disabilities desire independence, intimacy, and productivity—they told us so themselves—which isn't so different from what typically developing folks want. Even if your child has a more involved disability that would make dating difficult, she should still know how to protect herself and keep herself safe. There are many aspects of reproductive health, like safety, healthy friendships and relationships, boundaries, consent, and appropriate behavior, that are important to discuss even if dating and marriage are not in the cards.

when

SHOULD THIS BE DISCUSSED?

It's never too early to begin discussions, even if they are simple explanations of body parts and their functions. We find that many individuals with disabilities never receive any information about reproductive health, which can lead to frustration, anger, inappropriate behavior, loneliness, and depression, while also putting the person at risk for abuse. If they do receive information, it is often limited, not tailored to their learning needs, and negative in nature. Informal conversations can arise when you're least expecting them—perhaps a family member is pregnant or a scene in a movie sparks interest.

Let's acknowledge the elephant in the room.

It's important to reflect on your own morals, values, and beliefs about love, sex and dating.

Think back to your own childhood. Who gave you your first ideas about sex, love, and dating?

Many people cite family, friends, media, and faith communities as sources of such information. Some people received very little information, as sex is a taboo topic. Is this something you'd like to be different for your own family?

Now think about how your attitudes have changed over time. Perhaps once you got married, you realized sex was a lot different than in the movies. Or maybe your parents were never open about this topic, leaving you to learn from peers.

Each family has its own set of morals, values and standards. This guide is not designed to tell you what those should be—only to help you convey them in an effective manner.



Ebony's Story

Meet Ebony Deloach, a self-advocate in her early 30's who is passionate about issues within the disability community.

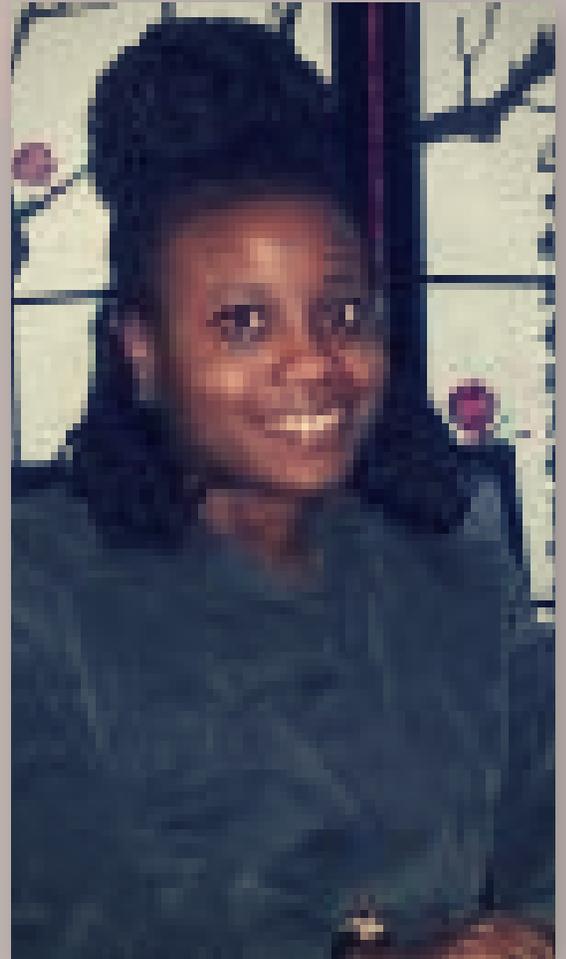
"That myth that we don't need companionship, that we just need friends...we grow up. We don't stay 5 years old forever," she says, speaking to the misconception that people with disabilities do not desire intimacy or romance.

An active volunteer in her community, Ebony says people make assumptions about her due to her disability, one being that she is childlike.

"It makes it hard if [parents] don't see you as an adult," she says. "People have relationships. Sometimes they can be unhealthy, but it's up to the child to make the choice."

Although she's currently single, Ebony says she has dated people with and without disabilities.

*"I think it's time.
We're in a new
era. It's time to
open up
discussion."*



BIGGEST CONCERNS

4

PARENTS FACE

We asked parents: When it comes to love, sex and dating and your child, what concerns you most? Hear what they said—and how this resource can be used to address concerns.

1

Someone will take advantage of my child.

This is a valid concern—people with intellectual and developmental disabilities are more likely to be sexually abused than their typically developing peers. It's hard to gather accurate statistics, but some sources have reported that **up to 80% of individuals will experience abuse in their lifetime.**

Children, teens and young adults should understand how their bodies work, what kind of behavior is appropriate in what setting, and what to do if they are being abused. Education is the key to prevention.

If you do nothing else, make sure your child is equipped with the knowledge, skills and confidence to know if abuse is occurring, and who to tell if it is.

here's a tip

Be straightforward. Avoid explanations like, "The stork brought you to us." Our children tend to think literally, and this can confuse and mislead them.

2

Information about sex will corrupt my innocent child.

"She doesn't understand what it means to be in love."

"He's a 7-year-old in a grown man's body."

Sentiments such as these are common in the world of disability. And it's no wonder—our kids can be very trusting, friendly, seemingly innocent, and enjoy material intended for much younger audiences. But remember, having a disability does not preclude someone from experiencing puberty. Your son or daughter might not understand the intricacies of relationships **the way you do**, but he or she still has hormones and innate desires. Our world is full of messages about dating and relationships. Our children see couples every day. It is naive to think they have not noticed that companionship is a significant part of life for many people. With all of the messages in the media, in schools and on the internet, make sure you're communicating with your child about your family's values and morals.

3

How will I know if my child understands the information?

Making sure a child comprehends nuanced information about dating, relationships, safety and appropriate behavior may seem like a riddle with no answer. However, think back to how you have successfully taught your child other skills and knowledge. Activities found later in this guide promote interactive learning by asking your child to name appropriate behaviors for people in their lives. Have them explain in their own words what a healthy relationship should look like, or encourage them to identify loving, healthy behaviors while out in public. Give your child the benefit of the doubt—you may not think he or she is retaining information, but so often we underestimate cognition in those with disabilities.

• teachable moments •

A "teachable moment" is an opportunity to educate that arises spontaneously. Perhaps a love scene in a movie sparks a conversation about consent or contraception. Or a song comes on in the car with questionable lyrics. Current events can also be great gateways for discussion. Asking a young person how they feel or what they would do in a certain situation can be valuable in assessing their understanding of social norms and appropriate behavior.

• here's a tip •

DON'T shame your child for acting on natural urges. DO establish expectations for appropriate behavior. Some behaviors are only to be done in private. This means the door is closed and no one can see you. Bathrooms at school or work might not be truly private. Reinforce expectations of privacy by knocking on the door before you enter, and affording your child time alone.

4

How will I know what to say?

It's a pretty safe bet that most parents feel uncomfortable when discussing the birds and the bees—but hopefully you now see why it's essential to address sexuality.

If you feel embarrassed, say so! Being open and honest throughout this process will help foster trust and respect. It may seem silly, but practice having conversations in front of the mirror, with your partner, or with friends. The more you say the words aloud, the more comfortable you will be when you really have to say them. Consider asking if your child's physician can spend some time educating her, or recruit a trusted friend to help.

recognizing signs

OF SEXUAL ABUSE

Abuse is most likely to occur at the hands of someone the victim knows. In 2014, 77% of cases reported to a local crisis center were someone the victim knew.

Keep in mind that a child displaying these signs is not necessarily being abused. It is important to take them into context and judge whether they are out of the ordinary for the child.

Behavioral



- becoming overly concerned about their body
- new inappropriate sexual behavior
- replicating the act on themselves
- increased sexual conduct

Physical



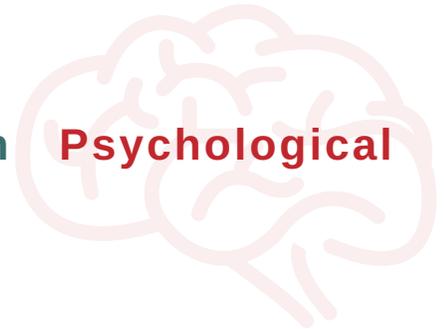
- genital pain, itching, discharge, or bleeding (potential symptoms of an STI)
- stomachache, headache, unexplained sore throat, or other physical complaints
- changes in monthly menstruation
- bruises or marks on the body

Communication



- new questions about sex, the body, or pregnancy
- repeating inappropriate/sexual words or phrases
- abuse can also include asking someone to send or receive inappropriate photos or messages

Psychological



- sleep disturbances, bed wetting, or new fears
- afraid of, or refuses to go places, with certain people
- excessive crying or attempts to run away
- increased aggression, agitation, or depression

be aware

Abuse is most likely to occur at the hands of someone close to the child. Be aware of someone who's "too good to be true"--they offer to babysit often for free, or constantly buy gifts for the child. Be cautious of those who seem overly concerned about a child's sexuality, developing body, or relationships; a person who attempts to isolate a child, maintain constant contact, or one who makes the child uncomfortable.

conversation examples

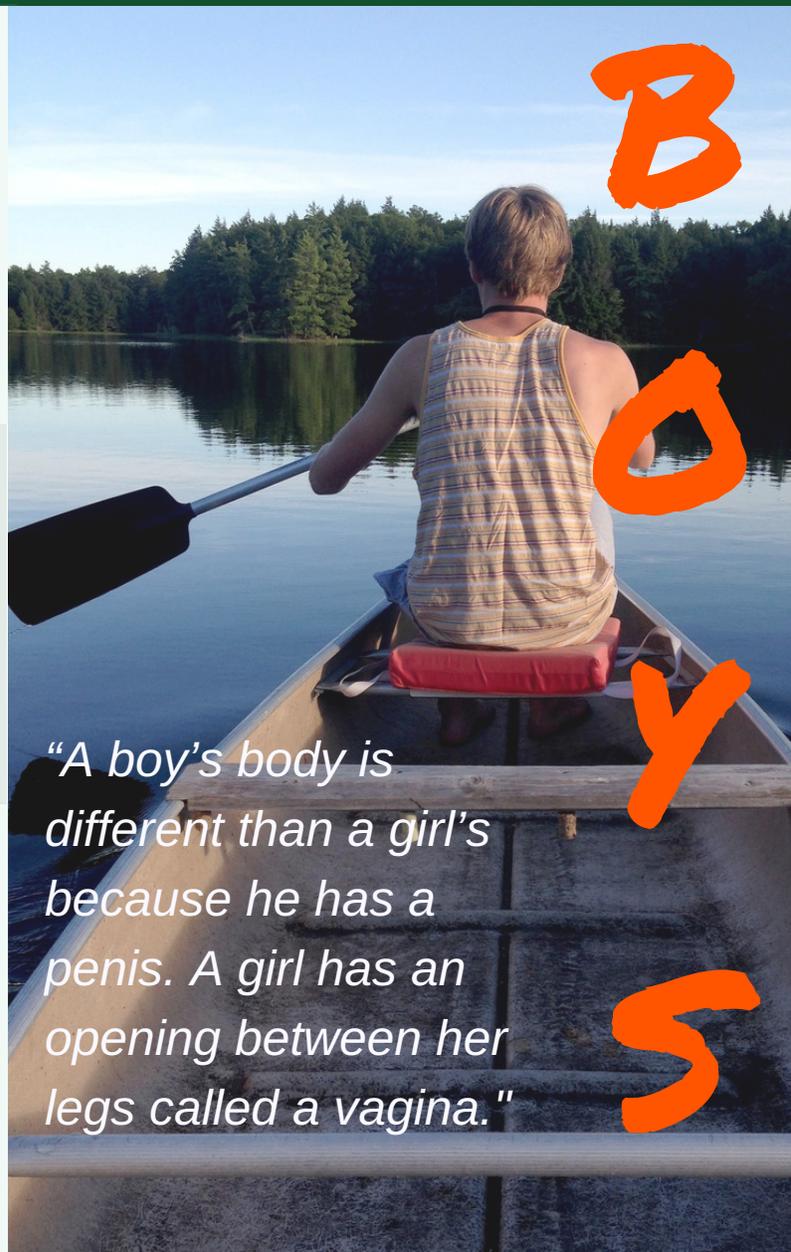
Hello

Use these straightforward, simple explanations to answer questions, begin conversations, and aid in understanding. Tailor them to fit your style and needs. Don't force a conversation if your child is uncomfortable, but DO look for opportunities to convey these important topics.

"Sometimes you will wake up in the morning and think you have wet the bed because all the sheets are wet and sticky. You haven't wet the bed--some semen has come out of your penis during the night. This is called a wet dream. Wipe the semen off with a tissue and wash yourself. Put your pajamas and sheets out to wash or air if they are messy."

"Lots of boys feel the need to rub their penis when they get an erection. That's fine. Most men and boys feel like that. It is called masturbation and can only be done in private. You should not touch your penis in public. You should wait until you can go somewhere private."

Your penis will get hard and stick up. Sometimes this will seem to happen for no reason at all. Others times it will happen when you are thinking about sex or girls or when you read something in a magazine. It can be embarrassing but it happens to most men. It is called an erection. An erection is a private thing. Do not ask everyone to look at it. Eventually it will go away."



"A boy's body is different than a girl's because he has a penis. A girl has an opening between her legs called a vagina."

A person wearing a grey sweater is holding a lit sparkler. The sparkler is bright and has many small sparks flying out. The background is a soft, out-of-focus blue.

“You don’t tell everyone you are having a period. It is something that is very special and private.”

GIRLS

“Soon you will also see blood coming out of your vagina--that means you are growing up. Most grown-up women have that blood coming out of their vagina for a few days every month. It is called having a period. It means your body will make a baby when you are ready to start a family on your own.”

“As soon as you see the blood coming out of your vagina, tell me or the teacher, so that we can take you to the bathroom and help you clean it up and put a pad on.”

“Sometimes you will feel a sort of ticklish feeling around your vagina that will make you want to touch it and rub it. You should wait until you can go to your bedroom and do that, because it is a very special and private feeling. You should not touch yourself on the vagina in public. This is called masturbation and it can only be done in private.”

B

O

T

H

“When two people like each other very much, they might want to hold hands and cuddle and kiss. Sometimes that makes them feel so good that they want to touch each other all over. A boy might then get an erection, and a girl’s vagina might feel moist. At this point it is best to stop and not go on touching each other, as it could lead to sex. Sex is not something you do out on a date unless you love each other very much and want to be together all the time. Also, there are a lot of things you two need to talk about, with each other or with their parents before you decide to have sex. Most people, especially when they are your age, just like to kiss and cuddle when they are out together.”

“People don’t have sex just to have babies. Usually they have sex because it feels good and they enjoy it, and because it is a way of showing love and affection for one another. They like to hug and kiss.”

B

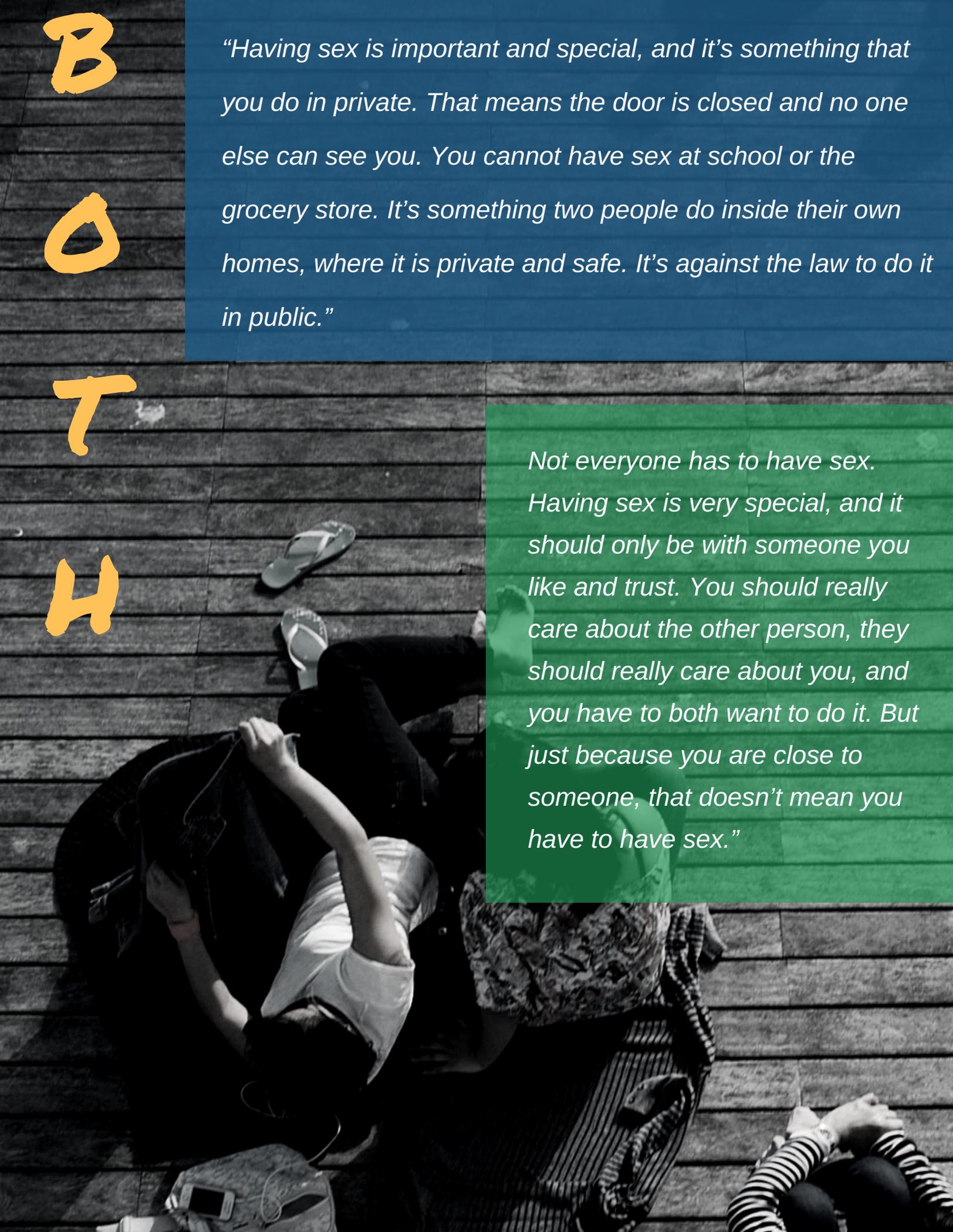
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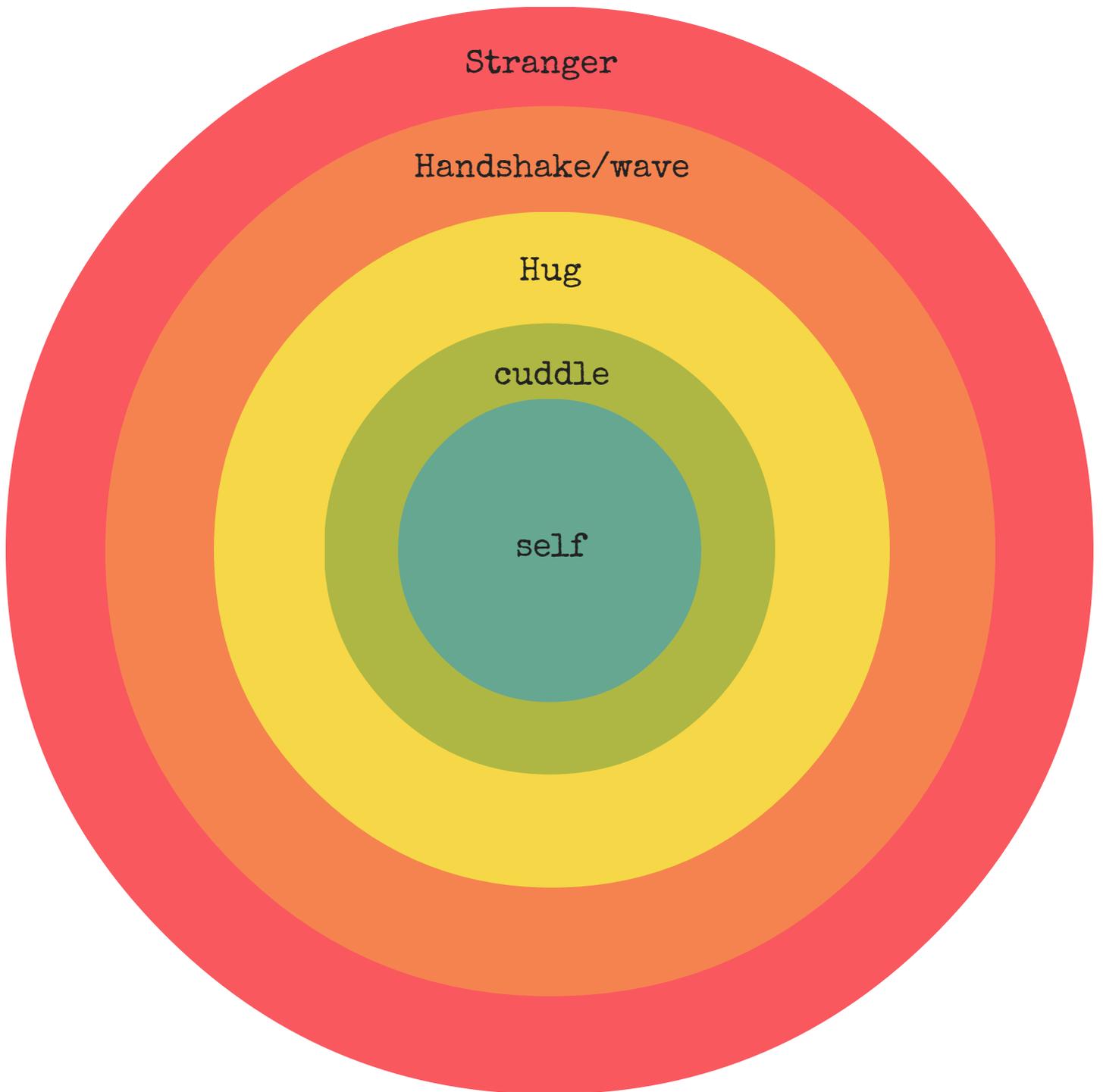
H

“Having sex is important and special, and it’s something that you do in private. That means the door is closed and no one else can see you. You cannot have sex at school or the grocery store. It’s something two people do inside their own homes, where it is private and safe. It’s against the law to do it in public.”

Not everyone has to have sex. Having sex is very special, and it should only be with someone you like and trust. You should really care about the other person, they should really care about you, and you have to both want to do it. But just because you are close to someone, that doesn’t mean you have to have sex.”



circles



See the next page for guidance in using this activity.

The Circles activity is a simple yet effective tool in teaching appropriate behaviors, safety, and boundaries. Individuals who do not use words to communicate or have more difficulty understanding abstract concepts can benefit greatly.

This activity is adapted from the Circles Curriculum, developed by Leslie Walker-Hirsch and Marklyn P.Champagne.

CIRCLE GUIDELINES

- *You are unique, and everyone has their own set of circles.*
- *No one can come into your inner circles (all except Stranger) unless you want them there, and you cannot enter someone else's inner circles unless they want you there.*
- *If someone is trying to enter one of your circles and you don't want them there, you have the right to say no.*
- *People can shift circles in either direction. Usually it's best if someone doesn't move from an outer to inner circle too quickly.*

BLUE CIRCLE

This is the most intimate and special circle. This circle is usually for one special person, like a boyfriend, girlfriend, husband, or wife. Children and relatives are not allowed to be in this circle, no matter what. You decide who is in this circle.

RED CIRCLE

This circle is for strangers. This means you do not know the person very well or at all. It is not a good idea for a stranger to move into your closer circles right away. Some people stay strangers forever.

GREEN CIRCLE

This is still a special circle. Some family members may be allowed in if they are close.

ORANGE CIRCLE

This circle includes people like neighbors, classmates, and people you don't know well. This can include adults or children.

YELLOW CIRCLE

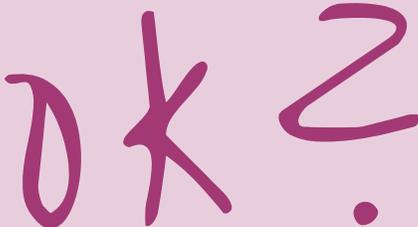
This circle can include people you are close to, like good friends, family members, and children. You should always make sure it's ok to hug someone. If someone tries to hug you and you don't want them to, you have the right to say no.

TIP

Use photos of family members, friends, and acquaintances, and cut out photos of strangers from magazines. Have your child indicate which circle each person belongs to. What behaviors are appropriate for each circle? Use this as an opportunity to instill your values--what does it mean for a person to be in each circle?

activities

Use these activities to encourage 2-way dialogue. They can be useful for children who do not communicate with words, or have limited verbal ability.

is it 

This game helps the child or young adult identify appropriate behavior and boundaries. For individuals who do not communicate verbally, use photos or drawings to help. Tailor the questions to fit your goals.

- **Is it okay to kiss the bus driver?**
- **Is it okay to hug a good friend?**
- **Is it okay to wave to the neighbor?**
- **Is it okay to hug a stranger?**
- **Is it okay to kiss your significant other?**
- **Is it okay to hug the store clerk?**
- **Is it okay to shake hands with someone you are being introduced to?**
- **Is it okay to hold a stranger's hand?**
- **Is it okay to hug your family members?**
- **Is it okay to hug someone you are being introduced to?**

consent

Consent is a vital concept that all children and young adults should grasp. Consent means that both **parties are of age, both people say yes to the activity, and no one said yes because they were forced to.** A person who does not use words to communicate can still consent.

It is **never** okay for sexual activity to occur between family members or children, even if everyone said yes.

In the eyes of the law, a person with an intellectual or developmental disability **may consent** to sexual activity. Do not assume it is automatically illegal.

You can instill the idea of consent by applying it in everyday situations: ask your child what outfit she'd like to wear. Ask if he prefers a pen or pencil. **Give your child choices** so that she knows she can say "yes" or no."

Who would you...?

In this activity, the child must use her knowledge of appropriate behavior and boundaries to determine which behavior is appropriate for a certain relationship. Conduct the activity verbally, or try using photos of family members, friends, and strangers taken from magazines and ask the child to sort them into these categories.

kiss?



shake hands?



hug?



wave to?



practice

Practice making a list of trusted adults your child could come to with a disclosure of sexual abuse. Make sure your child understands that sexual abuse can happen to anyone. It is not his fault, and it is important he lets someone know.

Family goals



In the next 7 days I will: _____



In the next 30 days I will: _____



In the next 6 months I will: _____

I would like for my child to be able to:

1

2

3

additional resources

Healthy Relationships and Safe Sex: Tips for Self-Advocates. Joe Meadours, 2006.

Making Sense of Sex: A Forthright Guide to Puberty, Sex, and Relationships for People with Asperger's Syndrome. Sarah Attwood, 2008.

Sexuality and People with Intellectual Disability. Lydia Fegan, Anne Rauch, and Wendy McCarthy, 1993.

South Carolina Campaign to Prevent Teen Pregnancy, teenpregnancysc.org

STARS: Skills Training for Assertiveness, Relationship-Building and Sexual Awareness. Susan Heighway, Susan Kidd Webster, and Marsha Shaw, 1988.

Understanding & Expressing Sexuality: Responsible Choices for Individuals with Developmental Disabilities. Rosalyn Kramer Monat-Haller, 1992.



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The Arc of South Carolina promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.