

Hello, and Welcome to the Flexible Mind Therapy Podcast.

My name is Joe Falkner, and I will be the host for this discussion on topics including Autism Spectrum Disorders and related areas, executive functioning, and cognitive rehabilitation.

I am a speech-language pathologist with over 25 years of experience working with individuals with communication, cognitive, and social difficulties. I've worked with individuals in a variety of environments, including: schools, clinics, Day Treatment settings, hospitals, nursing homes, etc... During my career as a speech language pathologist, I have specialized in working with individuals with ASD. I am a Certified Autism Specialist through the International Board of Credentialing and Continuing Education Standards. I currently have a small private practice in St. Paul, Minnesota.

Thank you for joining me for these discussions.

On this inaugural broadcast, we will begin discussing a subject that may seem a bit unusual for this podcast. We will begin today discussing Sexuality and ASD. I say begin, because this is such a complex discussion that we will be taking several podcasts to cover its many facets. Like politics and religion, discussions of Sexuality can be quite daunting, and engender many uncomfortable feelings. But, few things are more important for individual's development across their lifespan as is sexuality. Mature, fulfilling relationships that meet the individuals' social, emotional, and sexual needs are often the logical extensions of the social skills work that we begin with individuals with ASD when they are younger.

We will begin today by trying to wrap our arms around what sexuality and sexual health are, as well as introducing the importance of having discussions about sexuality with individuals with ASD. Sexuality is a multidimensional construct and involves much more than behavior with a partner. It also includes sexual knowledge, self-image, thoughts and feelings, values, attitudes, beliefs, behaviors, relationships, etc... (Nichols & Byers, 2016) (Koller, 2000).

According to the World Health Organization (WHO), "Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" (1975).

“Sexuality is the essence of being a male or female; it is the lens through which a person views the world! There are biological, medical, social, psychological, spiritual, cultural, and legal aspects to sexuality, and these aspects differ depending on where, when, and how you live; who is raising you; and what is personally important to you (WHO, 1975).” (Walker-Hirsch, 2007) Sexual Health is “...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.” (WHO, 2006)

As you can see, sexuality is a complex construct, and goes far beyond sexual intercourse. It can, in fact, be seen as a fundamental aspect of who we are, encompassing our relationships (including familial, friendships, and intimate), our sense of self, and how we identify with various groups (including gender identity and sexual identity). It is in many ways a basic human right, and its healthy development and expression can be seen as a human rights issue. (Hingsburger, 1995) (Wortel, 2013)

As important to our well-being as it is, sexuality, and its many aspects, can also be a very uncomfortable subject to talk about. We so often limit our thinking around sexuality to sexual intercourse, and miss the richer complexity of the topic. Sexuality is heaped with taboos and mores that are informed by our religious, cultural, and societal beliefs. Because of our beliefs, and how we limit our thinking around it, sexuality, and so many of the words related to it (such as Gender Identity) are emotionally laden terms. (Walker-Hirsch, 2007) As we think about discussing this topic, our own emotions color how comfortable we are with sharing information with others. Concerns about our own sexual knowledge can exacerbate our discomfort and lead to comments that are too vague to be of benefit to the individual or use euphemisms to describe sexual content.

One of the antidotes to this discomfort is, of course, knowledge. Knowledge won't necessarily change our beliefs. But, it will help us to understand both the

importance of this discussion, as well as dispel some of the myths that lead to some of the anxiety and fear around discussing sexuality. One of the key myths that knowledge can address in the area of sexual development is that of the “big talk.” You know, that one big discussion where all things about sexuality will be discussed with the teen. The one that is immortalized in all of those teen movies with the uncomfortable parent and teen stumbling through a discussion of sexuality that is vague and meaningless. Knowledge can help us to understand that there are many opportunities throughout the lifespan of the individual that parents can influence and inform the individual on sexual development.

Walker-Hirsch does a wonderful job of discussing sexual development in her book *The Facts of Life...and More: Sexuality and Intimacy for People with Intellectual Disabilities*.

“Genetic sex is determined almost instantly after conception. The genetic sex of the developing cells depends on the genetic material that is contained in a sperm when the sperm meets the egg. And so, sexual development and sexuality begin, but they continue to be influenced prior to birth.

Before an infant is born, its sexual systems are developed. Male and female organs begin to differentiate from each other during the embryonic stage of development, between 2 and 8 weeks. By the fourth month of development many specific sex organs are identifiable in both male and female fetuses (Vander Zanden, 2000). In addition to sex organ development, some aspects of sexuality are decided before a child is born-aspects over which a parent has had very little control-for example, genetic sex, atypical genetic combinations, delivery complications or injuries, and sensory experiences related to sexual stimulation.

After the birth of the child, environmental, cultural, and social influences come into play to influence sexuality. Some of these influences include:

- How the child is carried, nurtured, and cared for
- How the child is dressed, groomed, and toileted
- How the child expects to be touched and handled
- How long the child is allowed to cry
- The kinds of toys and stimulation that the child enjoys and receives

- How the rest of the world interacts with the child as either a boy or a girl

As you can see, many important lessons of a child's sexuality education are taught long before puberty. Parents and family members are the first, most influential and most important sex educators of young children. How parents regard each other and their children and how parents teach their children to enjoy and regard their bodies are important parts of early sexuality education. And the expectations and interactions parents and their children have “with others in their social world all contribute as well.

The following list includes some of the many factors that influence social and sexual expectations that are in action long before a child enters school, and way, way before puberty appears on the horizon:

- How family members give and receive affection to and from the child and each other
- How privacy and modesty are expressed at home
- How family members demonstrate and communicate being happy, sad, angry, or afraid, as well as more subtle emotional messages
- How family members argue and make up from arguments
- How family members interact with friends and social contacts outside of the family
- How family members interact with authority figures
- How family members teach each other (Couwenhoven, 2001)

Sexuality education at home does not usually come in the form of a formal class or an easily identified lesson. It is usually established through training and the promotion of acceptable behaviors that consider the many elements of a busy household.”

Between birth and two years of age, children engage in a process of discovering their bodies. They may touch their genitals for self-pleasure/self-stimulation. Over time, they will adjust their self-stimulation to conform with the external reactions of others. They will seek to initiate and respond to primary caregivers physical touch, through hugging, cuddling, clinging, nursing, dressing, and playing. (from Hartman, 2014; and Realmuto & Ruble, 1999)

Between 2 and 5 years of age, children will continue exploring their bodies. They may touch their genitals in public and rub their genitals for relaxation. Some reflexive sexual responses may be noted (for example, erection or lubrication). They may show increased curiosity about the differences between men and women, and may demonstrate some curiosity about private parts. During this period, there will be an increase in the naming of body parts and functions and a desire to view others' nudity. There may be questions about how babies are made and delivered, joking about genitalia and body functions, and a fascination with "obscene words". There may be some jealousy of the intimacy shared by parents. There is an increase in playing games such as 'doctors and nurses' and 'I'll show you mine ...' i.e. showing genitals to peers and exploring peers' genitals with consensual exploration of same age peers' bodies. Children at this age may imitate parental interactions that express affection, and continue to respond to others' touch, including hugs and cuddling. (from Hartman, 2014; and Realmuto & Ruble, 1999)

Children between the ages of 5 and 10 years continue to demonstrate curiosity about their bodies. They may masturbate for pleasure, and demonstrate an increased desire to engage in this self-stimulation in private. They may engage in increased discussions regarding sexual behavior with peers. Children at this age also begin to adhere more to their peer groups' style and to gender roles in clothing and play. (from Hartman, 2014; and Realmuto & Ruble, 1999)

Puberty usually occurs in girls between the ages of **10** and **14**, while in boys it generally occurs later, between the ages of **12** and **16**. As can be seen from the what has already been discussed, many aspects of sexuality have already begun to be experienced long before puberty begins. Along with the influences that Walker-Hirsch discusses, these activities and experiences form the base for later development.

Children between 10 and 14 years continue with sexual exploration with same and opposite sex peers (generally in fashions that are hidden from adults). They may think, talk, and dream about sex. They may watch sexually explicit material and masturbate to orgasm. They may begin dating, kissing and petting. (from Hartman, 2014; and Realmuto & Ruble, 1999)

Children between 14 and 18 years of age continue to masturbate for pleasure. They may become more self-conscious, and they may be more concerned with

“fitting in” with a particular peer group. Body image and self-esteem issues may arise. They may continue to have sexual wishes and fantasies, and may begin to engage in actual sexual intercourse. (from Hartman, 2014; and Realmuto & Ruble, 1999)

Throughout this developmental sequence, there are many opportunities for parents to share information and guidance. Providing information gradually to individuals is an excellent way to provide a foundation for later discussions about more complex and adult sexual matters. This also takes the pressure of the parent around having the “big talk.”

The influences and developmental sequence of sexual development that I just shared fit very well for individuals who are neurotypical. But, what about for individuals with Autism Spectrum Disorders? In future podcasts, I hope to discuss specific extrinsic and intrinsic factors that influence the development of relationships, intimacy, gender identity, and sexuality.

But, it is important here to understand that most individuals with Autism will express a desire to be in a relationship, to be intimate, and/or to engage in some form of sexual activity (whether that be self-stimulation, such as masturbation, or with a partner). “As with other individuals, those with ASD grow and mature along many developmental lines. The social developmental line includes the development of sexuality, while the physical line includes that of puberty. Sexuality begins in infancy and progresses through adulthood until death. Each life stage brings about physical changes and psychosocial demands that need to be achieved for sexual health to be attained.” (Urbano, Hartmann, Deutsch, Polychronopoulos, & Dorbin, 2013)

Many individuals with ASD will develop at a faster rate biologically than they do socially, emotionally, and interpersonally. Their bodies may develop, and they may experience the hormonal changes that occur with puberty, at a time that is similar to neurotypical individuals. But, due to difficulties associated with ASD, they may lack some of the experiences that guide the social and emotional aspects of relationship and sexuality development. Their sensory challenges may make developmental activities like cuddling and hugging a challenge for them. They may present challenges for their parents during early development so that activities that influence development, such as being carried, nurtured, groomed,

handled, and comforted, may be provided in idiosyncratic ways that may not provide adequate foundation for later development. They may demonstrate rigidity or rule-bound thinking that inhibits their overall development.

Many individuals with ASD lack the social sources (particularly from peers) that support relationship and sexuality development. This lack of social sources may be caused by: 1) their difficulties with social interactions limit their access to certain peer interactions, 2) in the peer interactions that they do have, the peer may see themselves as more of a helper, than as a full-fledged peer, and 3) concerns about the individual's vulnerability to abuse and/or exploitation can cause parents, caregivers and other professionals to limit individuals with ASD access to certain experiences with peers. (Brown-Lavoie, Viecili, & Weiss, 2014)

In addition, individuals with ASD may be viewed by parents, caregivers, and other professionals, as being asexual or perpetually immature. Expressions of sexual development may be viewed through the lens of aberrant behaviors, which may be punished. Parents of some individuals with ASD may experience concerns that their child's expression of sexuality at different ages may be viewed as aberrant behaviors by others. This paradox can lead to fears and anxiety for the parent, caregivers, and other professionals, that may inhibit the imparting of relationship and sexual knowledge. (Nichols & Byers, 2016) (Tissot, 2009)

As can be seen from today's discussion, sexual development in general, and in particular for individuals with ASD, is complex. As I previously mentioned, in future podcasts I hope to discuss more about the specific intrinsic and extrinsic factors that can influence relationship, gender identity, and sexual development, as well as some ideas for working with individuals with ASD on these important subjects. This broadcast will hopefully provide an initial jumping off point for these further discussions.

A transcript of this podcast, along with citations and a related bibliography, can be found on the flexiblemindtherapy.com website.

Thank you for joining me today.

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