

Hello, my name is Joe Falkner, and welcome to the Flexible Mind Therapy Podcast.

Over time, I plan to cover a number of different topics in these podcasts, including: information about diagnostic criteria and Autism Spectrum Disorders; biological and neurobiological correlates and co-occurring challenges; theoretical considerations related to ASD; co-occurring Mental Health Disorders and ASD; common and severe behaviors; Transitions topics and ASD; and Evidence Based Practices for addressing the needs of individuals with ASD. In addition, I hope to cover topics related to executive functioning, including: background, executive control systems, and other executive functions; and cognitive rehabilitation, including: information about attention, memory, problem solving, and metacognition. I began with the topic of sexuality, sexual health, relationship development, and gender identity and individuals with Autism Spectrum Disorders because I recently presented in Duluth, Minnesota at Minnesota Association for Children's Mental Health annual conference on these subjects. What was readily apparent from the discussion of participants, and their questions, was that there was a dearth of accessible information about these subjects, and there was a desire from participants to learn more. Hopefully, these podcasts, and the resources that I cite, will serve to help further discussions on these important topics.

In the first podcast, we discussed neurotypical development of sexuality and introduced some of the difficulties that individuals with Autism Spectrum Disorders may have in their development. In the second podcast, I reviewed the first intrinsic factor that can influence sociosexual development, and that related to the first diagnostic criteria from the DSM-5, persistent deficits in social communication and social interaction. I reviewed some of the social factors influencing social difficulties, including difficulties with: theory of mind, social immaturity or social naivete', intuiting the "hidden curriculum in these areas, understanding nonverbal communication and social contexts; and language use and understanding.

As part of the discussion of social immaturity or naivete', I mentioned the work of Dave Hingsburger (1995), and his concept of the "prison of protection." The "prison of protection" is built, often unintentionally, by others around the

individual with ASD to protect them from victimization. This protection is meant to protect the individual from sexual information, decision-making, society, and relationships because they are seen as “inherently” vulnerable. Paradoxically, this protection makes the individual with ASD more vulnerable, and actually increases the risks of victimization. This concept leads into our discussion topic for today: Ableism, which is the first of the extrinsic factors which impacts on sociosexual development.

Like all of the topics that we will be discussing, Ableism is a complex topic, and I will be providing, at best, an introduction to the topic today. And, like many of the topics this one can be quite sensitive for people. The purpose of the discussion today isn't to shame or blame anyone. It isn't to make us feel bad for the things that we may have done. It is to raise awareness of an area that we have a fair amount of control over, and that is our thoughts, attitudes, statements, and actions. I have chosen to use person-first over identity-first language for my podcasts up to this point. This is not necessarily an advocacy for the use of one language convention over the other. As a speech-language pathologist, I often write reports where the convention is to use person-first language. The debate over this topic is outside the scope of this particular podcast. But, as I discuss the importance of respecting the individual's self and identity, I felt this was worth acknowledging.

Ableism is a form of discrimination or prejudice against individuals with physical, mental, or developmental disabilities that is characterized by the belief that these individuals need to be fixed or cannot function as full members of society (Castañeda & Peters, 2000). Gill (2015) further refines the concept by providing this definition: “Ableism in its most broad interpretation reflects discrimination or oppression of disabled people, which can take the form of denial of rights and access and the perpetuation of stigma, hatred, and othering.”

When we see these definitions, we may believe that they don't describe us or anything that we do or think. But for a moment, consider a few comments that I have heard over the years. “In the real world, he wouldn't be able to get away with a behavior like that.” Or maybe, “If they just worked harder, or applied themselves, they wouldn't have all of the problems they complain about.” Or

finally, “That family just doesn’t get it. They need to understand that we (meaning the care providers/therapists/teachers) know better.”

Now, you might say that these aren’t so bad. Or, that we just have the individuals’ and families’ best interests in mind. But, for a moment, picture yourself in that person or that family’s shoes. How much would it devalue your experiences, your very existence, to hear others talk about how you aren’t in the real world? How cold and unfeeling does it feel to hear someone tell you that the problems you experience are because you aren’t adequately applying yourself? How would you feel if you were this family, and told that you should “just leave it to the experts?” Each of these statements exacerbates the stigma and “otherness” of the individual with ASD.

Now, that isn’t to say that this is strictly a professional problem. I have met many family members and community members who focus on the differentness of individuals with ASD. They may discuss the behaviors of others who are around the individual with ASD in a critical fashion (such as, “He has so many individuals in his class who have ASD. He needs to be around more neurotypical peers.”) At first blush, this may seem to be describing the desire for inclusion. But, in many ways, this imparts a judgment of others with ASD (or other neurodiversities) that connotes that being with peers with ASD is less valuable than being with neurotypical peers.

Attitudes, such as those that I have described, can have profound impacts on the individual’s sense of self and identity. Westland (2015) discusses our sense of self forming from the synthesis of interoception (or information from inside of the body) and exteroception (information from outside of the body). A powerful source of information from outside of ourselves are the people in our environment (including, family members, teachers, caregivers, the media, etc...). If those people who are around the individual with ASD hold attitudes and make statements, such as the ones that I described earlier, then the individual with ASD may form a sense of self that either sees themselves as a victim, or sees themselves as inherently less valuable than if they were neurotypical.

“The term identity comes from the Latin noun “identitas,” which means the same. The term, referring to a person's mental image of him or herself thus implies some sameness with others in a particular way. Each individual may have a number of identities, such as an ethnic identity, a religious identity, or a national identity.” (Steensma, Kreukels, de Vries, & Cohen-Kettenis, 2013) Individuals with ASD who have the sense of self that is based, at least partially on, the attitudes of others that have been described will have difficulty developing a coherent identity (or sameness with others in a particular way). On the one hand, they may struggle identifying with others with ASD, while on the other hand they may see themselves as different than neurotypical individuals so will struggle identifying with that group. This can further feelings of isolation and anxiety.

It was my distinct honor to be the Clinical Director for a charter school in Minnesota called Lionsgate Academy. Lionsgate’s mission is to, if I paraphrase it a bit, help prepare individuals with ASD for adulthood; to help them develop mature and successful relationships, work, home and community lives. I watched many individuals with ASD develop a strong identity with their school community, and with a peer group, that was unlike anything that they had experienced in previous schools.

Walker-Hirsch (2007) discusses a phenomenon that occurs for many individuals with developmental delays where their typically developing peers change the nature of their friendships with the individual with a developmental delay from a more peer-to-peer friendship to a helping friendship. She goes on to say that: “It is especially important for teachers and family members not to inadvertently devalue friendships that their children with disabilities have with other children with disabilities by overvaluing their friend-ships with typically developing same-age peers. Some parents may brag to their friends or relatives that their children have only typically devel-oping friends. Some parents may even condone statements by their child that it is acceptable to be afraid of students who have disabilities. By the same token, praising certain individuals for their academic accomplishments or their driving ability may convey an unspoken mes-sage about the greater desirability of having friends who do not have dis-abilities. There is room in a person's life for many different kinds of friends, each with valuable assets to offer. Most of us choose to have rela-tionships with people from many

diverse cultures and practices to enjoy and learn from. However, we also align ourselves with friends who evidence a common identity. Relationships often develop in a natural and intuitive way by participation in mutual interests or working side-by-side over a period of time.”

There is nothing inherently wrong with inclusion. But, we must remember that within the promise of inclusion, there is the benefit for “all” students due to their exposure to a diverse community, with eclectic experiences. It is this diversity that helps raise all of us up. The value needs to be conveyed to everyone involved (teachers, parents, and students) of having a diverse community that honors everyone’s ability to contribute.

I had the honor of hearing Daniel Wordsworth, who currently serves as the President and CEO of the American Refugee Committee, speak so eloquently to this very subject a few years ago at a benefit. He said the following:

“What is at the root of being human?

1. *Human beings are truly wondrous things, wondrous beyond measure.* There are so many different chords, different stories and ways of explaining existence. As a Cambridge professor of Astronomy once told me: there is an amazing concord between the smallest and largest things in our universe – there are the same number of atoms in one human, as humans that could fit into the sun.
2. *Every person brings into this world a gift that belongs to them.* We have come on a long journey to reach here, and each person carries a gift into this life. Community is formed with all people bringing a unique gift, and to thrive, it must encourage each person to use their gift. If a community denies someone their gift, they are robbing them of a gift that has traveled a huge distance to arrive here. A gift-giver’s humanity is wrapped up in the sharing of their gift, and if you deny them that, you deny their humanity.”

These observations are true regardless of the individual’s race, ethnic background, religion, gender, sexual orientation, gender identity, disability, etc... If we open ourselves to the gifts that may be given by all members of our community, we as a community, as a society, have the opportunity to grow. At

the same time, we help to affirm the value of these individuals' selves and provide opportunities for these individuals to develop strong identities.

You might ask what all of this has to do with sociosexual development in individuals with ASD. Surprisingly, quite a bit actually. Tissot discussed the following in a 2009 article on establishing a sexual identity for people with autism spectrum disorders: "Societal attitudes may present more hindrances to an adolescent's sexual development than the limitations resulting from the disability. Some individuals see those with disabilities as 'childlike or asexual' or even as individuals without any interest in sexual activity. Others see this group as a potential threat to non-disabled peers or are worried about protecting the disabled adolescent from potential harm or abuse. (And others,) may be afraid that teaching (the) child to establish a sexual identity will result in an increased interest and increased activity, although the research literature does not support this conclusion... When the views of the public influence too strongly the delivery of services, it can hinder or significantly limit the quality or type of instructional provision provided, leaving a gap in knowledge for this group. Many adolescents with disabilities receive inadequate information about sexuality or do not understand the information presented."

Other authors have agreed with Tissot's assertions (Attwood, Henault, & Dubin, 2014) (Harader, Fullwood, & Hawthorne, 2009) (Henault, 2006) (Hingsburger, Just Say Know! Understanding and Reducing the Risk of Sexual Victimization of People with Developmental Disabilities, 1995) (Hingsburger & Tough, Healthy Sexuality: Attitudes, Systems, and Policies, 2002) (Nichols & Byers, 2016). Nichols & Byers (2016) wrote: "For many people, sexual functioning and relationships is not an easy topic to either discuss or address. In other words, the topic of sexuality is often associated with a feeling of discomfort, which prompts avoidance. So when it comes to thinking about sexuality and disability (including ASD), a common response has been to just not think about, plan about, or educate, promote, and support it. This is compounded by many stereotypes and misconceptions that linger today, including the beliefs that, as a group, individuals with ASD are asexual, not interested in sexual relationships, and not capable of forming romantic attachments. Nonetheless, sexual well-being is an incredibly important aspect of healthy development, personal safety, and overall adjustment of people with ASD."

Barnett (2014) in her research on the “Sexual Citizenship on the Autism Spectrum” interviewed 24 individuals with ASD who were aged 18-61. She elucidated two broad areas of Ableism that were found to limit the participants, and gave a number of examples for each of these areas:

1. “Structural ableism: refers to experiences generated through the implementation of social structures that privilege particular abilities and the people who demonstrate them at the expense of those who do not. Examples of structural ableism included:
 - a. the construction and organization of public spaces that do not accommodate sensory differences
 - b. inadequate or inaccessible transportation options;
 - c. inadequate access to health care, especially for ASD--related services, sexual/reproductive health, and medical transitioning
 - d. narrow diagnostic frameworks mediating access to supports (i.e. qualify for benefits programs or services);
 - e. laws and policies that use “safety” as rationale for exclusion (e.g. school expulsion, assignment to an institution);
 - f. generally inadequate and inaccessible sexuality education, that in particular failed to address gender and sexual variance or disability--relevant concerns such as flirting and sensory sensitivities;
 - g. service providers that were paternalistic and/or ignorant about autism;
 - h. limited availability of services for adults on the spectrum or services addressing specific adult concerns (e.g. parenting).
2. Cultural ableism: refers to experiences generated by the exercise of social norms and cultural beliefs that value particular abilities and the people who demonstrate them at the expense of those who do not. The experiences of structural ableism discussed in the last section represent the uptake of cultural ableism in institutional spaces, making the effects of these norms more difficult to combat. Examples of cultural ableism included:
 - a. the pervasive experience of being misunderstood due to the privileging of neurotypical ways of experiencing, understanding, and communicating about the world;
 - b. paternalistic treatment (e.g. talking to participants as if they were children);
 - c. the belief that accommodating participants’ needs was a “burden” on others or the sole responsibility of the participant;

- d. social ostracism;
- e. lack of access to disability--relevant representations and/or knowledge, particularly sexual representations/knowledge;
- f. the idea that sexuality and/or procreation are directly linked with being typically abled, i.e. (sexuality is inappropriate for persons with cognitive disabilities, persons with cognitive disabilities are inherently more vulnerable to abuse--exploitation, disabled persons are unable to partner and/or undesirable as partners, Autistic persons are not competent parents, Autistic persons should not reproduce because they might "transmit" autism to their child, particular, normative sexual experiences are fundamental to a life with essential human qualities – and for passing as typically abled."

It may be easy to see how some of these examples of structural and cultural ableism impact on the sociosexual development of individuals with ASD (such as the inadequacy or inaccessibility of sexual education and the idea that sexuality and procreation are directly linked with being typically abled.) Others may be more difficult to see how they impact on this development. Going back to the discussion of "self" and "identity" development from earlier, we can intuit that the treatment of individuals with ASD "paternalistically" can lead to feelings of frustration and may fragment their association (or identity) with any particular group. Inadequate public spaces that do not accommodate sensory differences limit the places that one can go to "on a date" or where one can meet up with friends (which is often a way that we learn and develop relationships). Inadequate or inaccessible transportation options may leave the person with ASD dependent upon others for transportation and may limit their ability to participate in many of the aspects of relationships. These are just a few of the ways that these examples of ableism can affect sociosexual development.

A good way to summarize the discussion today may be related from an excerpt from Hingsburger and Tough's (2002) article: "...it is becoming clear that healthy sexuality needs to be conceptualized in terms of healthy selves. Popular wisdom stating that, "You can't love someone else until you love yourself," supports this conceptualization, yet many who are responsible for the care of people with disabilities are averse to the notion of encouraging healthy sexuality. Although it is an overgeneralization to state that the field of service provision to people with

disabilities in its entirety has passed along prejudices against the expression of sexuality of people with disabilities, indeed against those with disabilities themselves, it would be a vast understatement to say that this bias is a problem only of the very few.” We must identify how the attitudes, words, and actions of both our institutions and ourselves perpetuate ableism. We must work to address these attitudes, words and actions, so that individuals with ASD may not be limited by these as a part of their development of healthy and mature sociosexual selves.

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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