Hello and thank you for coming in today.

I wanted to talk with you a bit about Sex Ed and Autism Spectrum Disorders.

Now, Sex Ed is about more than just having sex.

In fact, if the whole of sex ed was represented by a yard stick, then only the last inch is really about sexual intercourse. (Walker-Hirsch, 2007)

You might ask yourself, "What makes up the rest of the yard stick then?"

Sexuality encompasses more than just sexual behavior. It includes self-image, emotions, values, attitudes, beliefs, behaviors, relationships, etc. Our view of sexuality changes constantly in response to interactions, experiences, and formal and informal education. (Koller, 2000)
What are the barriers to effective sex ed with individuals with ASD?

Great question! And a very complex one.

To answer this question, let me first ask you a quick question about Sexuality, Gender Identity, and Relationship Development.

On a scale of 1 (doesn't bother you) to 5 (it could make you lose control), how comfortable are you discussing these topics?

The words sexuality and gender identity are emotionally laden ones! Pairing these words with similarly emotionally laden terms, (such as Autism Spectrum Disorder or Mental Health), can engender great discomfort, fear and uncertainty in parents, professionals, teachers, and administrators. (Walker-Hirsch, 2007)
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).
Abelism affects how neurotypical individuals perceive and understand the individual with ASD.

The Individual with ASD can be perceived as perpetually young, immature, or even innocent.

This can lead to the withholding of Sex Ed information, either deliberately or unintentionally.

Research demonstrates that individuals with ASD have less access to appropriate, evidence-based sex ed.

Although the intention can be to protect the person, what actually occurs is that the person is made more vulnerable.

‘Societal attitudes may present more hindrances to an adolescent’s sexual development than the limitations resulting from the disability’ (Murphy and Young, 2005, p. 642).
I can't believe that societal attitudes are the only barriers to effective sex ed and sexuality in people with ASD.

And you would be absolutely correct. There are other intrinsic and extrinsic factors that affect effective sex ed and sexual development.

A couple of additional extrinsic factors, other than Ableism, that can have profound effect on sexual development are social isolation and lack of training and materials for caregivers.

Due to the social challenges that individuals with ASD experience, they are more likely to be socially isolated or rejected by peers and others.

Because of this isolation and rejection, they may have less opportunities to learn from peers and others about developmentally appropriate sexuality.

The lack of these social sources means that individuals with ASD are left to obtain the majority of their sexual knowledge from non-social and often unmonitored sources, and in the current study, were more likely than peers to obtain knowledge from television/radio, pornography, and the internet (depending on the type of sexual knowledge). Some of these non-social sources have been found to lead to inaccurate sexual knowledge (Berten and Van Rossem 2009).
And how about the lack of training?

The lack of training for caregivers and other professionals can lead to anxiety, fear, and dread around the subject of sexuality.

Parents may fear that their child's expressions of gender and sexuality may be misinterpreted and pathologized by others, leading to the rejection of their child and labeling of their child as being deviant.

Parents may also feel like they lack the support and skills necessary to have an effective discussion with their child about sexual development.

Professionals and other caregivers may feel similarly unprepared. In addition, they may be concerned about the risks and liabilities of teaching sex ed.

Collaboration is the ideal context to provide sexuality education to individuals with ASD. Parents and professionals may find comfort in working together to provide quality sexuality education. Through collaboration, parents can be designated as the responsible party for providing explicit sexuality education that is consistent with their family's culture, religion, and/or other beliefs, while professionals are responsible for teaching skills for social development in the school and community settings. In combining efforts, maintaining communication, and building relationships with the family, positive outcomes are more likely. (Travers & Tincani, 2010)
Can you tell us more about the intrinsic factors?

Certainly, the intrinsic factors really break down into four areas: Social, Cognition, Regulation, and Behavior.

And, like the extrinsic factors, each impacts on, and is expressed by, the individual with ASD differently based on their own unique "self".

The "self" I'm referring to here is the person's essential being that distinguishes them from others. It relates to the qualities that make a person unique.

It certainly relates to the presentation of the individual's ASD. But, it also relates to other factors like personality and identity.

As the saying goes, "If you've met one person with Autism, you've met one person with Autism." The key for me here is person, or individual. Their ASD is only one part of what makes these individuals unique.
What are some of the social factors?

Individuals with ASD may experience delays in Theory of mind development. This may adversely affect their development of important relationship skills such as empathy and trust.

Due to their social challenges, they may be gullible and vulnerable to misinformation on relationships from peers.

They may not understand the "unwritten rules" of relationships, dating, marriage, sex, etc...

They may have difficulty with the social-emotional reciprocity involved in relationships and intimacy.

These, as well as other social challenges (e.g., difficulties with nonverbal cues, reading social contexts, and difficulty with emotional processing), may exacerbate the rejection, isolation, and loneliness that the individual experiences.
The individual may also have difficulties in the area of regulation. This may particularly be seen related to sensory-motor skills.

1. Sex is intrinsically a sensory act.
2. Sensory sensitivity and tactile sensitivity in particular can affect sexual relationships.
3. Soft physical contact may be unbearable.

Sensory components of intimacy may be difficult:

1. This is called interoception
2. It relates to our awareness of body and emotional states
3. It includes awareness of sexual arousal, emotional awareness, romantic love, empathy, etc...

Difficulties with awareness of internal sensations and states can also have significant impacts.

This includes:
1. Bilateral coordination
2. Body awareness
3. Motor planning/praxis

A third area of regulation relates to gross and fine motor skills.

Closely associated with social. It includes:
1. Emotional control
2. Emotional awareness
3. Emotional expression
4. Emotional labeling

The final area of regulation that I will mention is emotional regulation.

Along with the social-emotional and cognitive components, the areas discussed related to regulation can at times help to explain what is behind the behaviors that may be seen exhibited by the individual with ASD.
There are a number of cognitive areas that may also affect individuals' sexual development:

1. Literal thinking
2. Black and white thinking
3. Special or circumscribed interests
4. Difficulty with mental flexibility
5. Detail vs big picture orientation
6. Difficulty with executive functions

Some of the cognitive factors are considered endemic to most individuals with ASD.

1. Tend to understand relationships from an intellectual standpoint
2. Because of difficulties with flexibility, may need clear boundaries, definable structures, and concrete rules.

These endemic factors can have significant impacts on relationship and sexual development.

3. Friendships and relationships may lack the structure and clear boundaries that some individuals with ASD need.
4. They may idealize the concept of love, having learned it from books, television, or the internet.

These issues can be exacerbated when the individual with ASD also has an intellectual disability.

In the past, there have been few materials addressing relationships and sexuality that have been specifically created to address the cognitive and learning styles of individuals with ASD. There has been a proliferation of materials, particularly in the area of puberty, over the last decade or so that have increasingly been designed with individuals with ASD in mind.
I get concerned that my son's attempts at sexual expression and relationships will be interpreted by others as somehow deviant.

I can understand your concern. And, it is one that other parents of individuals with ASD share. It is important to know that not every person with ASD has behavioral challenges in this area.

For those individuals with ASD who do have behavioral difficulties that may be manifested by:

1-Public masturbation
2-Masturbation with unusual objects
3-Removing clothing in public
4-Touching others inappropriately/unwantedly
5-Indiscreet discussion of sexually inappropriate topics

Blasingame, 2011

And, as I previously noted, often these behavioral difficulties are the result of difficulties in social-emotional, cognitive, and/or regulatory skills.

Behavioral difficulties are best addressed through a thorough functional behavioral assessment that takes into account all of these skill areas, possible functions of behaviors, and any co-morbid conditions (e.g., anxiety) that may also be impacting the individual.
Earlier you mentioned gender identity, how is that affected

Excellent question. Gender identity (GI) can be seen as the way a person aligns (or doesn’t align) in their head with their understanding of the options for gender

The gender identity of autistic adolescents can be a source of conflict. Some adolescents with AS do not have the natural tendency to question their identity. (Renault, 2016)

1- Gender development is a complex process involving biological, psychological and cognitive elements influenced by social norms.
2- Social isolation and difficulty attending to social cues may impact awareness of gender cues

3- They may be more fluid in their GI
4- They may demonstrate variance in gender expression
5- They may struggle with self-awareness
6- Rigid, inflexible thinking may drive their understanding of gender

In some individuals with ASD this may be experienced as Gender Dysphoria. The diagnosis is characterized by a strong and persistent cross-gender identification, which is often associated with distress of one’s own biological sexual characteristics and assigned social gender role. Strang, et al, 2016, have proposed some of the first guidelines for the identification and treatment of individuals with co-occurring ASD and gender dysphoria.
So, what can we do?

Well, the first step is what we've just done which is to provide some training in the area of sexual development and individuals with ASD.

The next step is to determine what team is available for providing sex ed to the individual with ASD, and what the roles of different team members will be.

Parents are always the primary sex ed educators for their children. Schools and other professionals can provide support, resources, and supplemental training and interventions for individuals who require it.

Parents may not feel prepared or capable of providing adequate sex ed to their child with ASD. At these times, other team members may take on more active roles in the sex ed process.

A proactive, well-considered approach will always be better than a reactive one. Open communication between all parties, especially with the individual with ASD, is the best way to ensure success. Even with preparation, there is still a chance that behavior difficulties will arise. But, with a planned approach and open communication, there is a better chance of responding earlier and avoiding the stigma and shame that may result from, and complicate the treatment of, a behavior difficulty.
It's important that evidence-based practices are used in the provision of sex ed to individuals with ASD.

Practices that have been found to be beneficial include:
1. Behavioral interventions
2. Modeling (including video modeling)
3. Scripting

What has been focused on by many writers is the need for early, and on-going intervention; the need to be concrete and consistent; and the need to teach in real-life contexts.

Programs like the Circles Curriculum and the Healthy Relationships Curriculum already incorporate some of these best practices in their design.

Unfortunately, budgetary constraints may prohibit the use of these more expensive programs. There are a number of low cost and free resources that may be used to develop comprehensive programs. The key is getting started. Guidelines from the Future of Sex Education and Sexuality Information and Education Council of the United States can be excellent places to start (particularly with school age individuals). These guidelines provide age/grade specific recommendations for skills to be worked on/developed.
Before we wrap up, are there any questions?

I know you mentioned this earlier, but won’t discussing this increase the likelihood that my child might start engaging in these behaviors?

I understand your concerns. But, there is no research that discussing these topics increases the likelihood that individuals with engage in sexually acting out behaviors.

In fact, research has demonstrated that medically accurate and appropriately-delivered sex ed can decrease the rates of teen pregnancy and STD.

Thank you for your time and attention today.

If you would like to discuss more, or have any questions, please feel free to contact me at:

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