

Autism Society of Alberta

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Autism and Sexuality: Overcoming Barriers & Supporting Healthy Expression



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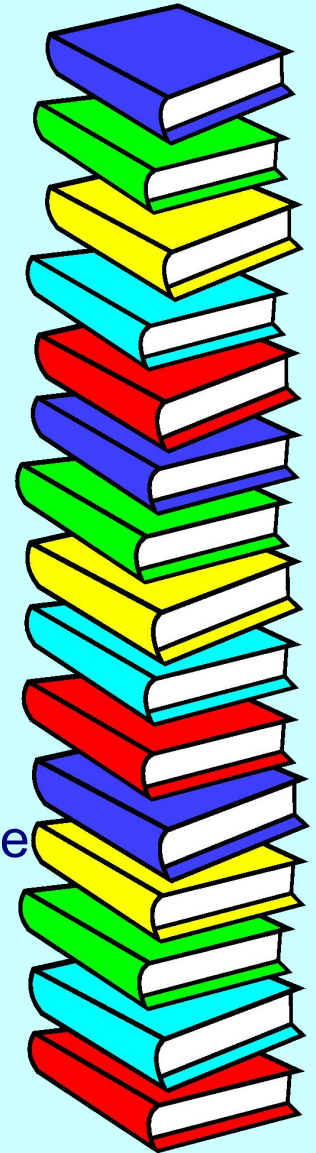
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Faculty of Rehabilitation Medicine

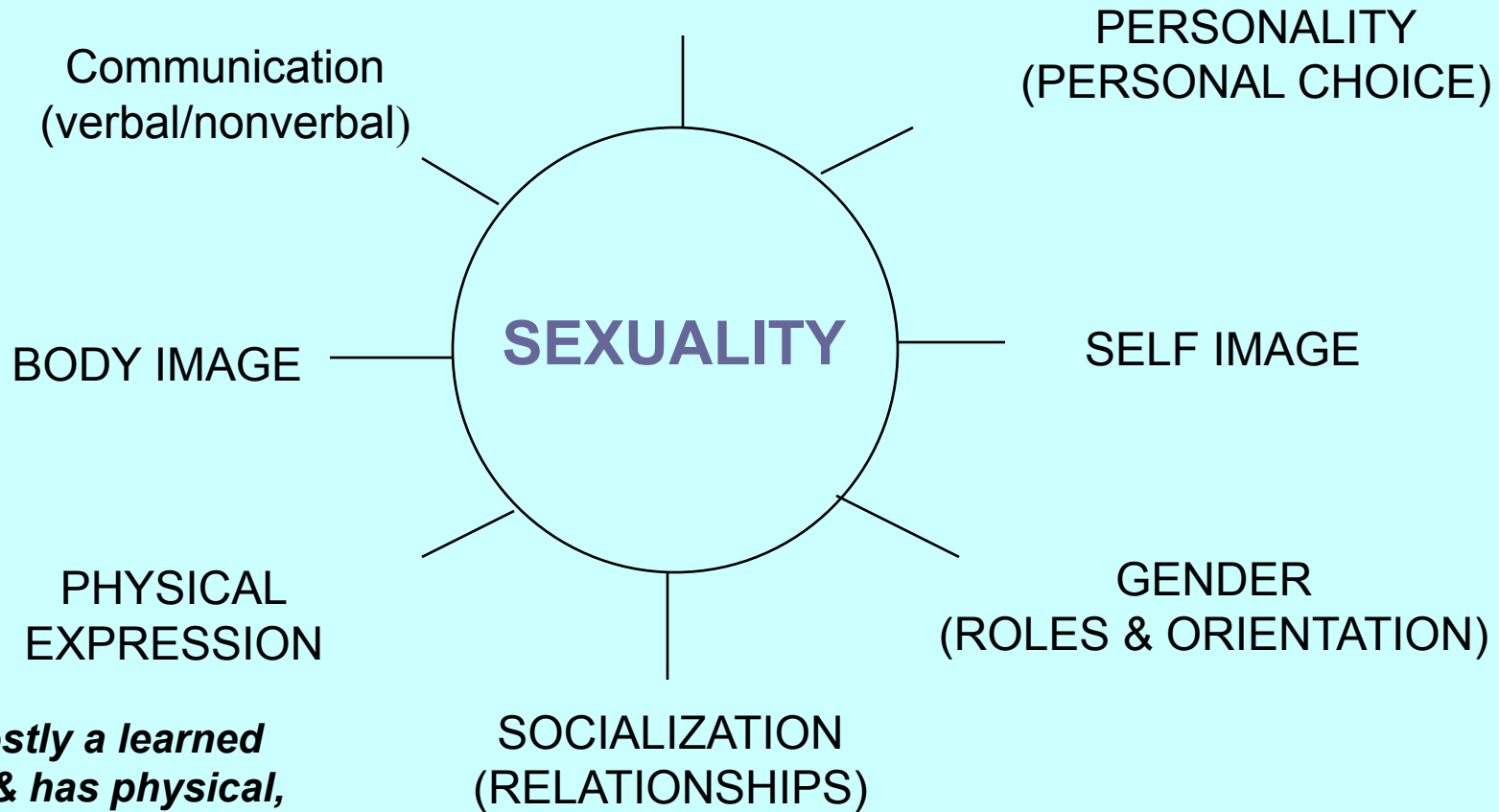
Session - Overview

- Introductions
- What is sexuality and sexual identity
- Autism
- How autism impacts Sexuality
- Healthy sexual expression
- Barriers to Sexual Expression
- Issues around Consent and Control
- Sexual Health Intervention
- Supporting Sexual Expression and mitigating Inappropriate Sexual Behaviours
- Unique Issues re: Sexual Health Intervention with Autism
- Helping Individuals Express their Sexuality
- Summary



Sexuality: The whole person including sexual thoughts, experiences, ideas, values and imaginings

Beliefs and Values



Sexuality-mostly a learned phenomena & has physical, emotional and spiritual aspects



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We Are All Sexual !

- “It's important to realize that discussing sexuality will not create sexual feelings in people.
- Those feelings are already there because sexuality is a part of each human throughout the entire life cycle”
(Kupper, p. 9, 1994)

Importance of Promoting Healthy Sexuality

- Unhealthy and abusive forms of sexuality may prevail.
- The inability to develop healthy sexuality can lead to or worsen mental disorders such as anxiety, depression, and adjustment disorders, as well as impaired self-esteem.
- Restricting sexual expression can lead to other forms of “acting out”
- Can put individuals at risk for sexual abuse and exploitation, STIs, and unplanned and unwanted pregnancies.

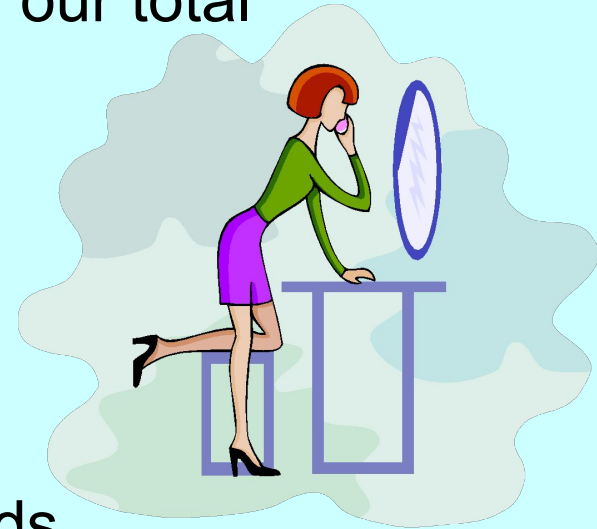
(Evans & Conine 1985)

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Sexual Identity

We are in continual process of discovering who we are in terms of our sexuality: Critical part of our total identity. It includes:

- gender roles
- orientation
- self esteem/body image
- confidence level
- relationships – personal, family and friends
- roles as child & adult
- perception of self – gender
- context - our environmental bubble

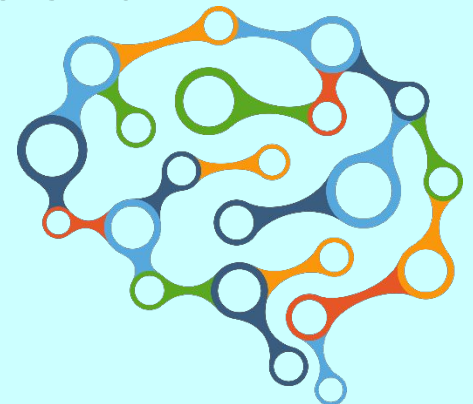


For reference

Neuroanatomy of Autism

- The hemispheres of Autism brains have slightly more symmetry than those of a typical brain (lateralization = flexible function)
- Autistic Brain has increased synapses which creates miscommunication among neurons that correlates with impairments in learning
- The cerebellum is one of the key brain regions affected - known for its role in movement, it is also important in higher cognitive functions such as language and attention and learning

(C. Rossi 2021, Watanabe et al., 2019)



For reference



Neuroanatomy of Autism

- Grey matter (information processing) ripples into peaks and troughs called gyri and sulci, Autism brains there is significantly more folding in the left parietal and temporal lobes as well as in the right frontal and temporal regions
 - In autism there's short-range over-connectivity and long-range under-connectivity
 - reduces neuronal network connectivity, allows weakly connected regions to drift apart, with sulci forming between them
 - timing of brain activity is impacted, the signals from one region of the brain to another get blurred in time
- Overall the brain processes information differently shows less coordinated activity

For reference

Autism

- Autistic people show the entire range of sexual behaviors
- Core traits of the spectrum
 - differences in social skills,
 - sensory hypo and hypersensitivities, and repetitive behaviors,
 - some Autistic individuals might develop quantitatively atypical sexual behaviors and interests.
 - Knowledge does not translate into action – or translates into atypical action
 - Can have more hypersexual and paraphilic fantasies and behaviors

(Koller, 2000, Schöttle, et al 2017)

E Autism and the BRAIN – Functional Implications → Sexuality

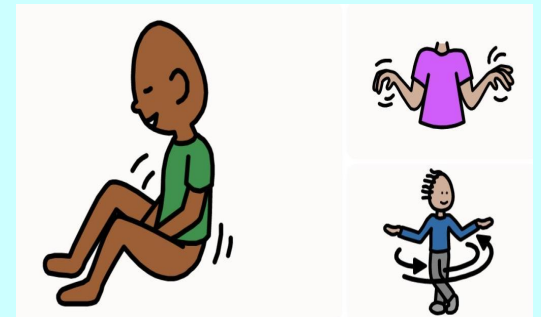
- Difficulty to figure out solutions spontaneously
- Difficulty to control sexual impulses, esp. in social situations
- Difficulty to apply consequences from past actions (behavior mode?)
- Difficulty with abstract concepts e.g. relationships
- Differences in processing information – sexual situations
- Difficulty storing and/or retrieving information – Learning Sex Education
- Could need frequent cues, requires policing by others
- Helps to talk to self out loud, often needs feedback
- Some autistic people have more roller-coaster emotions, exaggerated (**pleasure centers fully formed-** not higher sex drive but need to act on sex drive or limited self control)
- apparent lack of understanding of emotional responses, need external motivators (predatory behavior)
- Difficulty to weigh pros and cons when making decisions
- socially (sexual) inappropriate behavior (Koller, Kellerman, 2008)

E Autistic People

- Children grow up with normal hormone surges
- Their social development may not match their biological age
- Differences create challenges with relationships, communication and sensory system's
- Differences can also interfere with judgment, impulse control and various other cognitive process.
- In addition, many don't receive adequate sexual health education some don't get any SHE at all
- Social differences limit informal opportunities to learn about sexual health and sexuality
- Above - cause the person to be at high risk of becoming a victim, a perpetrator or both for Sexually inappropriate behavior (ISB). (Koller 2000, Kellerman 2002)

E Autism sensory differences

- Up to 100% of autistic people have sensory processing differences
- Many autistic people seek out sensory stimulation often referred to as 'stimming' through actions like rocking, spinning, finger flicking, hand flapping, etc
- It's important to note that stimming should only be discouraged if it poses harm to the individual or others; otherwise, it helps them regulate their sensory experiences.
- Autistic children may engage in sensory behaviours, such as touching or rubbing their genitalia, which should not be punished. Instead, establish rules for safe spaces like the bedroom or bathroom, allowing them the freedom to engage in such behaviours privately.



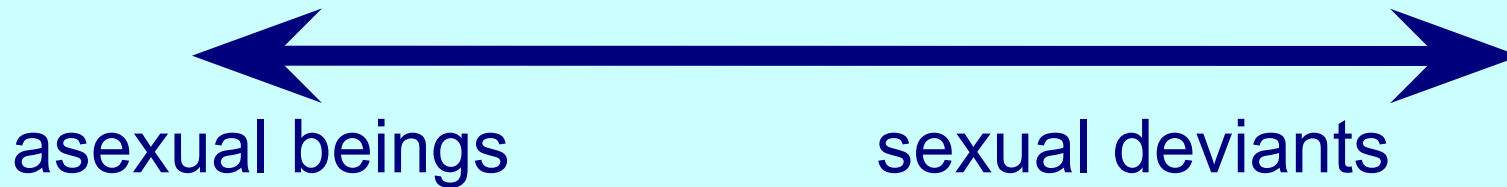
Features of Autistic Individual's that make them vulnerable to sexual abuse & exploitation

- Culture of obedience and compliance
- Challenges with socialization and understanding relationships
- Many different caregivers
- Sensory differences
- The need for help with personal care,
- An inability to defend and speak up for themselves,
- Lack of sex education and knowledge of normal social and sexual limits

(Aylott, 1999)

Sexuality & Autism

- E
- Autistic Children, adolescents, and adults are frequently seen as:



- Disability dilemma empowerment vs protection
- Many applaud advances of “mainstreaming,” “normalization,” and social integration; **however**, sexuality and sexual expression continue to be controversial and highly charged.

(Wolfe, 1997; Ailey et al., 2003)

Inappropriate Sexual Behaviors (ISB):

Inappropriate = as determined by society

1. boundaries - making inappropriate sexual advances
2. boundaries - inappropriate sexual touching,
3. Promiscuous and predatory sexual behavior,
4. exposing behavior,
5. compulsive sexual behavior,
6. voyeuristic behavior (i.e., peeping),
7. masturbating in public,
8. unusual or worrisome sexual behavior e.g. deviant and/or paraphilic behaviors

ISB - Cognitive Disability & Sexuality

- Mean age of onset of inappropriate sexual behavior (ISB) was 9-10 (Streissguth, et al. 2004)
- 40-50% of autistic children demonstrated inappropriate sexual behaviour (Ailey et al 2003, Streissguth, et al. 2004, Rasmussen et al 2007, Wolfe 1997)
- 50-55% of adolescents and adults had repeatedly displayed ISB. (Blaumbach, 2002, Streissguth, et al. 2004)
- 50% of individuals with CD had repeated problems with ISB (Kellerman, 2002)
- Approx 80% of individuals with CD had experienced physical and/or sexual abuse (Clark et al 2004)

Gender Differences - ISB

- Similar frequency rate of ISB reported for males and females
- Females ISB tends to be around and boundaries and promiscuity
- While males were likely to get in trouble with the law for ISB – more coercive and nonconsensual activities.(most absence of malice)
- Note: females were more likely to be victims of sexual abuse while male the perpetrators.
- Being a victim of sexual, physical abuse or violence has been found to increase the odds for ISB

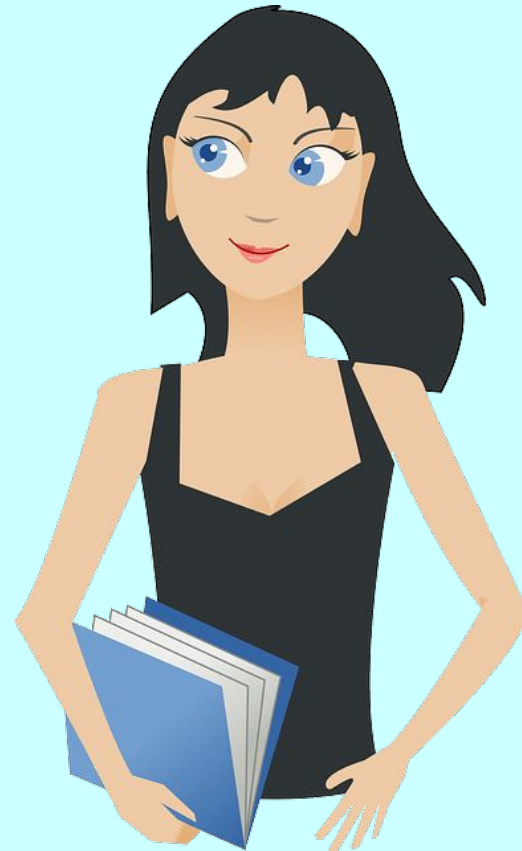
(Ailey et al 2003,Streissguth,et al. 2004, Wolfe 1997)

Healthy
Sexual
Expression




Inappropriate
Sexual
Behaviour

What's going to happen?



What's your greatest fear?



Intercourse
is just one tiny aspect of sex,
like one tiny planet in an infinite galaxy
of erotic possibilities

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Healthy Sex Vs Harmful Sex

Healthy Sex

Sexual Abuse and Addiction

Sex is a choice

Sex is an obligation

Sex is a natural drive

Sex is addictive

Sex is nurturing, healing

Sex is hurtful

Sex is an expression of love

Sex is a condition of love or devoid of love

Sex is sharing with someone, part of you

Sex is “doing to” someone

Sex requires communication

Sex is void of communication

Sex is private

Sex is secretive

Sex is respectful

Sex is exploitative

Sex is honest

Sex is deceitful

Sex is mutual

Sex benefits one person

Sex is intimate

Sex is emotionally distant

Sex is responsible

Sex is irresponsible

Sex is safe

Sex is unsafe

Sex has boundaries

Sex has no limits

Sex is empowering

Sex is power over someone

Sex enhances who you really are

Sex requires a double life

Sex reflects your values

Sex compromises your values

Sex enhances self esteem

Sex feels shameful

(McKinley Health Center, 2009)

What is Healthy Sexual Expression?

- Involves recognizing and celebrating that everyone is sexual
- Emotional and social communication/connection
- CERTS Model (developed by Wendy Maltz)
 - Consent – freely chose to engage in sexual activity
 - Equality – sense of power is equal with your partner
 - Respect – positive regard for self and partner
 - Trust – trust partner on both physical and emotional levels
 - Safety – you feel secure and safe within the sexual setting

(McKinley Health Center, 2009)

- Abuse/trauma
- Poor self-esteem
- Side effects of medication
- Paranoia
- SH Education?

Individual

Structural

Attitudinal

- **Harm Reduction**
- Social isolation
- Overprotective parents
- Controlled living arrangements
- Intentional policies in place preventing intimate relationships

- Limited circle of friends and social contacts
- informal/inappropriate sources of information
- Attitudes and comfort of Service providers

Barriers to Sexual Expression

Issues Around Consent and Control

- When an autistic person is unable to control sexual impulses and does not have the capacity of giving informed consent what do you do?



Ability To Give Consent Strongly Related To:

- Sexual knowledge
- Level of intellectual ability
- Social adaptive age
- Having participated in sexual health education courses

(Niederbuhl & Morris, 1993)

Self control: **For Reference**

Inappropriate Sexual Behavior

- Deficits in response inhibition imply limitations in the capacity for self control. Learning self-control is central to dealing with ISB (Ryan & Lane, 1997).
- But what if there is neuropsychologically a limited capacity for self-control?
- Individual can tell you what is right and wrong but does not follow own understanding
- Impact of external cues to help control certain behaviors

“Consensual ability” = Capability to give informed consent to sexual contact

- Evaluating an individual’s consensual ability should address the person’s ability to make a decision based on:
 - **knowledge of the nature of the sexual contact,**
 - **its possible consequences,**
 - **the social and moral context in which it occurs.**
- Contact where one or both parties lack consensual ability may be considered a crime
- It is expected that Staff are required to report all sexual contact between non-consenting individuals to the appropriate authorities. Niederbuhl & Morris 1993

“Sex drive may not match intellectual capabilities”

Issues around consent

For Reference

- Self-esteem
- Determining safe, effective and appropriate sociosexual interaction,
- Capacity to give consent
- The ability to identify what consent means
- How to give consent or deny it
- Education for individuals with regarding issues of consent can/should begin in childhood,
 - in ways that are age appropriate
 - take into account particular learning needs.
 - E.g. teach toddlers about good touching versus bad touching and teach older children about not allowing anyone to touch them without permission.

Graduated/Situational Consent

- Able to give consent to some forms of sexual activity that did not include for example sexual intercourse.
 - Protects against unplanned pregnancies
 - lessen the possibility of the individual contracting sexually transmitted infection.
- However is this appropriate???
 - by definition any sexual contact that is not consensual is considered assault.

(Niederbuhl & Morris 1993)

Capacity to Consent - Highly Contextual

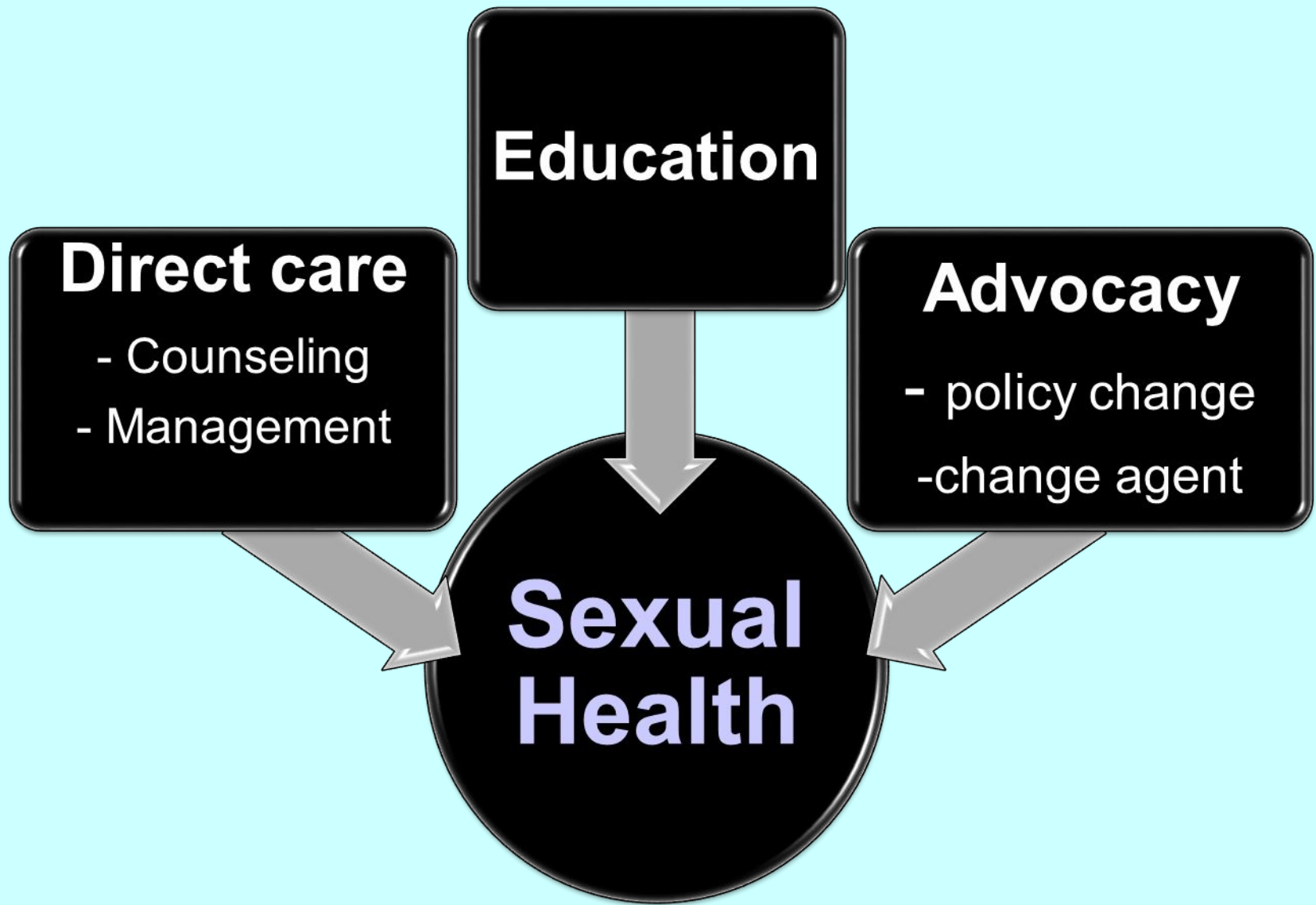
- once a person is deemed incapable of consenting, his/her opportunities for sexual expression become very limited due to the global nature of the determination.
- The “situational competency” allows argument that an individual may be capable of consenting to some forms of sexual contact. With a certain individual in a particular setting but not to other forms of sexual contact with the same or other individuals in other settings.
- Lawyers point out individuals with disabilities may be competent in this particular area even if they are not deemed competent in other aspects of their lives
(Bonnie, 1992, AAP, 1996)
- If individuals show by their behavior they wish to engage in certain forms of sexual contact, and if it is judged that this contact can improve quality life, then third-party consent should be sought (Kaeser, 1992)



E We Are All Sexual – Facilitating Healthy Sexual Expression

- Strength based approach rather than a deficit based approach
- Coping with urges
- Coping with loneliness
- Wanting to model what they see
- Acceptance and redirection
- Been different is OK
- Looking at options and alternatives
 - Clubs, exercise, healthy occupations and activities

Sexual Health Intervention



Programs vs Programing

What is the Goal ?



“Being programed” or internalization of skills?

Sexual Health Education (SHE)

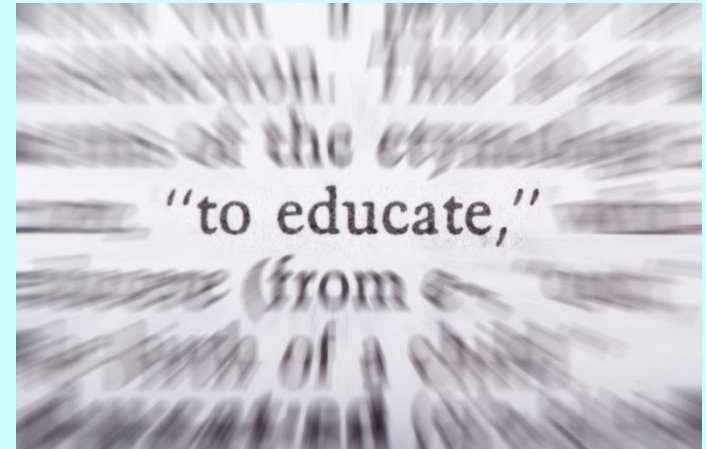
Benefits Include:

- Self Esteem and Empowerment
- Skill Building
- Improved Communication
- Setting the Stage
- Articulating Goals
- Preventing Negative Outcomes such as abuse

(Maurer, 2007; Sweeney, 2007)

SEXUAL HEALTH EDUCATION: Areas That Need To Be Addressed

- Rights and responsibilities of sexual behavior
- Dealing with current relationships,
- Sexual interactions and behaviors
- Social skills – assertiveness the right to refuse
- Orientation
- Body part identification
- Pregnancy, childbirth and abortion
- Sexually transmitted infections
- Contraception strategies
- Masturbation
- Sexual abuse
- Personal care and hygiene, Puberty, Menstruation
- Medical examinations (Ailey et al., 2003 L.; Sweeney, 2007)

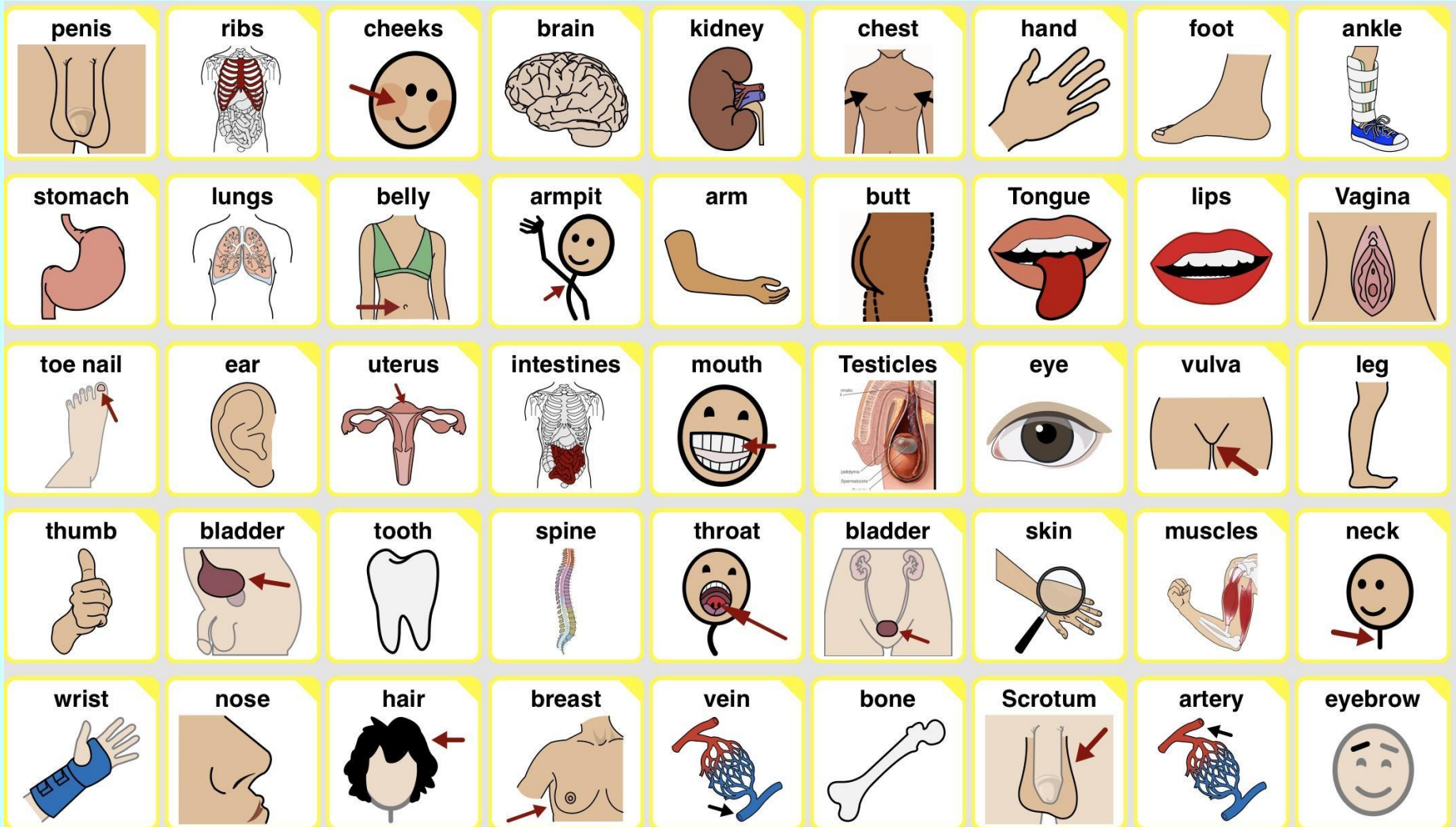




E Implementing Sexuality Education Programs

- **Content** - directed at the needs of the individuals involved
- **Teaching Methods**- need to take their abilities into account. Low literacy and other learning deficits are common
Sexuality information needs to be presented at the level that is meaningful to the client - concretely, simply, matter of fact, and repeatedly.

E Teaching proper anatomical names for body parts to all. Having these available in Robust AAC systems



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Addressing sexuality appropriately, taking into account an individual's developmental level, is crucial for the well-being of autistic people. It helps reduce the risk of sexual assault and exploitation.

The image shows a communication board interface with a dark header and a grid of icons. The header includes navigation icons (back, home, clock, search), a title 'Main List: Sexuality', and utility icons (lightbulb, refresh, mute, settings). Below the header is a search bar and buttons for 'Speak', 'Clear', 'Delete', and 'Share'. The main grid contains 50 icons arranged in 10 rows and 5 columns, each with a text label below it. The labels are: like, love, kiss, Sexuality Feelings, All Word Lists, hug, man, woman, sexuality, stroking, boyfriend, girl friend, gay, bisexual, straight, transgender, sex, date, private parts, intercourse, masturbation, protection, cuddle, yes I like it, and no stop.

like	love	kiss	Sexuality Feelings	All Word Lists
hug	man	woman	sexuality	stroking
boyfriend	girl friend	gay	bisexual	straight
transgender	sex	date	private parts	intercourse
masturbation	protection	cuddle	yes I like it	no stop

SPECIFIC SAFETY EDUCATION AND TREATMENT PROGRAMS

- Traditional Sex education content
- Impact of autism on sexuality
- information on STI (HIV / Aids) safe sex
- techniques for managing high risk situations
- Communication, assertiveness, self esteem
- skill building e.g.. demonstrations on condom use
- teaching clients to develop personal awareness of their situations
 - role playing
 - behavioural rehearsal
 - modelling

Sexuality Guidelines

- Treating this population as asexual or as children is ingrained in much of society that it creates a vicious circle. They are treated like children and then — **surprise!** — they sometimes behave like children.
- Accurate Age-Appropriate Information - Topics should be tailored to the chronological age of the person.
- Teach to express physical affection that is appropriate to their apparent ages.
- The teaching methods/tools should be at their intellectual abilities
 - concrete vs abstract
- Remember that Context is Everything


Maurer, 2007

INTERVENTION DEALING WITH SEXUALITY WILL IT WORK?

- Looking at “programs” for persons with Autism and ISB – nothing has been scientifically validated except the use of medication to control behaviors.

“If you keep doing what you have always done, you will keep getting what your have always gotten”

(J Potter)



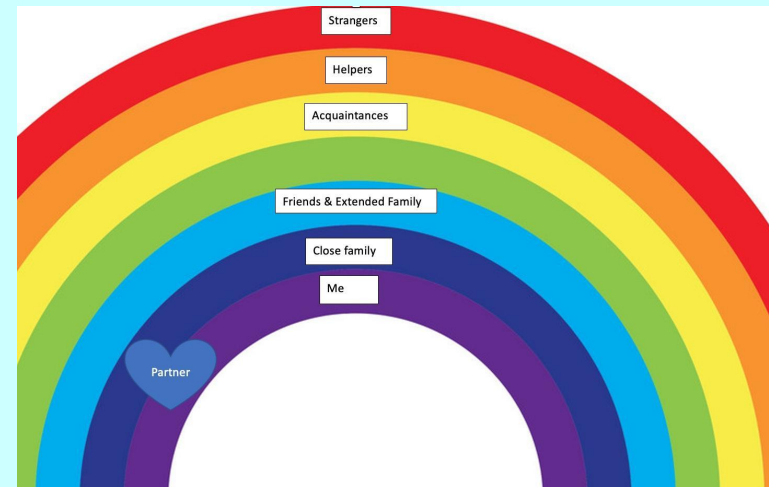
Sexual Health Education for Neuro Typical and Autistic Adolescents

- Typical SHE programs do not account for the unique differences
- SHE Programs for Autistic people tend to be ineffective in improving social decisions
- Unlike typical children, Autistic children will not outgrow social difficulties

Various resources that can be adapted: E

e.g. Boundaries Flip Book with Picture Symbols

Social Stories, Circles program- importance on considering the person and personalizing it to them and their needs





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Behavior Modification

- growing literature on the management of these problems with this population using behaviour modification methods
- However not all of these methods are appropriate
- E.g. negative reinforcement such as time out may actually reinforce the behaviour
- Fixed – interval reinforcement may be to insensitive to encourage inhibitory control

(Alderman & Knight, 1996)

Dealing with ISB – Short Term

- **One size does not fit all!**
- Deal with it immediately following basic societal principles
 - Public safety,
 - Safety of individual (emotional and physical)
 - Lessen future negative consequences
 - If the behavior is inappropriate in the context it occurs – stop it e.g. masturbation should be encouraged in privacy but stopped in public
- Explain and redirect – deal with it based on context – may not be the best time for a learning opportunity e.g. behaviour modification

What is causing the ISB?

- What are the triggers/motivation?
- Observed – Ask – talk to the individual and team – what patterns do you note?
- What they say may not be what they mean but there is still value
- Is sexuality the real issue?
- What needs are being met by the ISB
- What would be something they would prefer to do (ice cream or cake)?
- Replace stimulus with more appropriate stimulus
- Skills retraining

STRATEGIES FOR DEALING WITH ISB

- Individual-centered approach!
- General recommendations found in the literature and practice seem to have their basis in common (reasoned) sense.
- Interventions should be concrete and redundant, with lots of time for practice and repetition.
Tonneato (1997, as cited in Boland et al., 1998)
- However, in some circumstances, Autistic people failed to benefit from repeated exposure to training, showing most of their improvement in the first two trials. (Mattson et al.'s (1996)

Based on what you know (or think you know)

- Create a safe space— where almost anything goes
- Provide opportunity to meet needs – healthy sexual expression unique to the individual
- Provide triggers in safe environment where appropriate reactions are practiced
- Move out from safe space to meet non-sexual needs that are manifested as ISB
- Next address sexual needs that are manifested as ISB

Reality Check

Strategies When Sexual Health Education and Social Skill Training is Not Enough

- Develop a list of acceptable activities
 - Does not require Individual with /Autism to decode situation
 - Can be adapted to situation
- Provide a system to deal with the unknown
 - using supports
 - Teach self monitoring to identify cues where they would seek help
 - Identify safe people

Strategies When Sexual Health Education and Social Skill Training Is Not Enough

- Establish rules for home (safe space)
- Establish rules for public
 - Set and follow clear expectation
 - Simple yet critical issues (i.e. don't over do it)
- Provide opportunities for expression
 - Masturbation (schedule, cues)
 - General socialization (being with others)

Sexuality is not a Taboo subject – make it an everyday topic – nothing magical about it

Keys to dealing with ISB (on-going)

For Reference

- Stable and nurturing environment (home, school, social environment) is the most influential protective factor reducing by 3-4 times the risk ISB in children and adults (Streissguth, et al. 2004)
- Behavior Therapy and Education
- Parent and Service provider education and training
- Medications (anti anxiety, some stimulants, SSRI depression and compulsive behaviors, Neuroleptics (antipsychotic (tranquillizers))
- Support the healthy development of Sexual Identity

■ Helping Autistic people Express Their Sexuality

- There is no right or wrong way - but keep it professional!
- There is no right or wrong person who should do this ... but somebody should!
- Provide opportunities for expression
- The needs of each gender are usually different
- Masturbation acceptance/training shown to decrease tension and inappropriate behavior

(Thompson, 1994)

For reference: Dealing with Sexual Expression

Principles for Working with People with :

- With appropriate safeguards, sexual expression may be encouraged.
- Masturbation is normal sexual expression no matter how frequently and at what age it occurs
- All sexual activity involving the genitals should occur in private
- Private sexual activity is acceptable between consenting adults.
- Nobody is allowed to touch someone with a disability in any way without their permission
- Teach the difference between acceptable behaviors in a private setting and those acceptable in public.
 - Public-private errors - Stranger-friend errors

For reference: Dealing with Sexual Expression

- Providing a stable and nurturing environment
- Discuss boundaries with the person
- Rules about sexuality need to be simple, consistent, absolute, and concrete
- Role play and talk about how to handle social situations
- Explain the need for permission from the other person before engaging in potentially sexual behaviors
- Provide opportunities for safe, consensual sexual expression

(Streissguth et al., 2004)

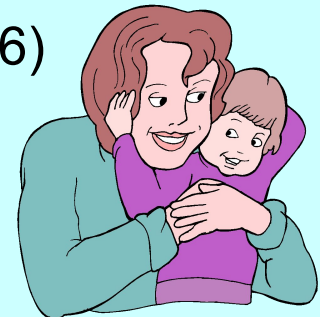
For reference: Dealing with Sexual Expression

- Openly discuss sexuality
- Reinforce appropriate and redirect inappropriate behaviours
 - Some behaviours are OK in specific contexts but not in others (ex: private vs. public)
- Allow for sexual experimentation at appropriate times
- Keeping an open mind e.g. same-sex behaviours,
- Consider the possibility that the person displaying inappropriate sexual behaviour may have been a victim of abuse at one point
- Service providers should help to normalize sexual behaviours such as masturbation - It is important not punish the person in your care for these behaviours.

For reference: *SEXUALITY EXPRESSION* *SUGGESTIONS FOR PRACTISE*

- Teach Sexuality as Positive and Pleasurable
- Discourage inappropriate displays of affection.
- Express clear behavior expectations that conforms with family and societal standards.
- Recognize the Importance of Feelings - Practice Appropriate Affection
- Discuss pleasure and affection when educating about sex.

(Maurer, 2007, APA, 1996)



Comprehensive Approach

- “Having a comprehensive definition of sexuality”
- Focus on both the life enhancing and harmful aspects of sexuality
- Consensual sexual activities viewed as normative, positive and healthy, not deviant – **BASIC HUMAN RIGHT**
- “Assisting individuals to be aware of the choices involved in sexual decisions”, such as “whether or not to be sexual and exactly what being sexual can mean”

Benefits

- Sex education and open discussion reduce vulnerability of individuals
- Non-judgemental
- Builds self-esteem
- May help develop social and assertion skills

(Harden, 2014; Tobin, 1997; Williams, Prior, & Wegner, 2013)



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Conclusion:

- Sexuality is a human right that is important to all individuals regardless of age, gender, orientation, or developmental level.
- Sexuality is closely related to a person's self-concept and self-esteem.
- To broadly address the development of healthy sexuality for Autistic people, the issue needs to be normalized, not ignored or avoided, which means involving family members, staff, and service providers.



Questions and Comments:



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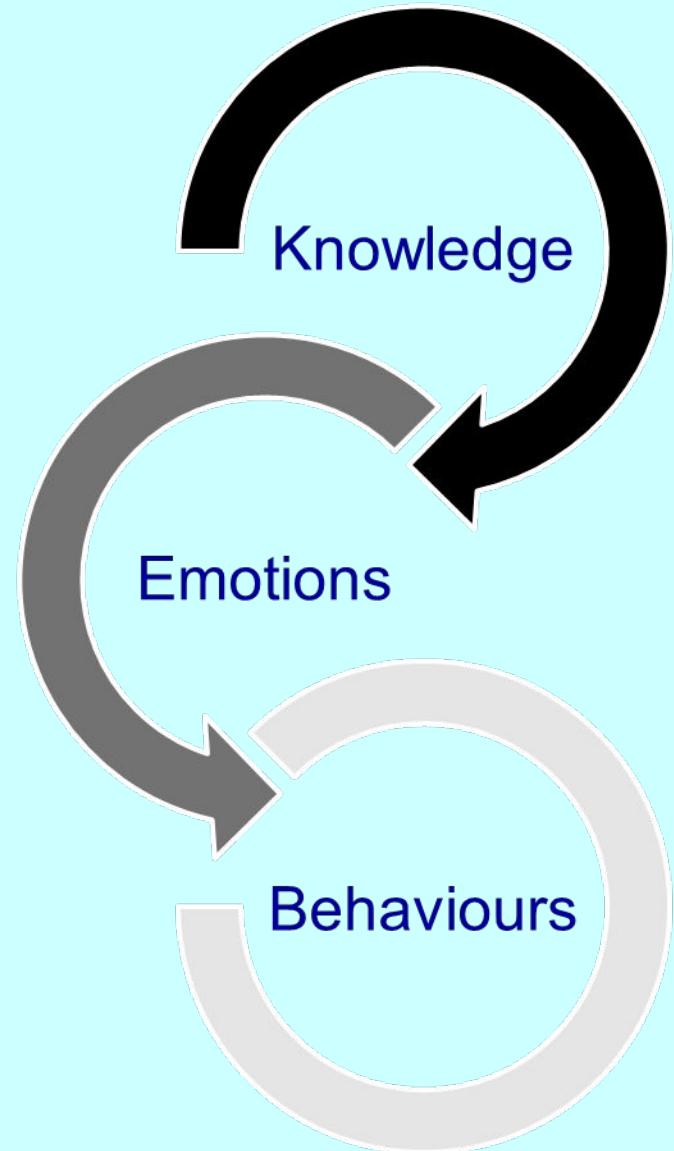
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Sexuality can be described from three aspects:

- **Knowledge and beliefs** - how much information we have about human sexuality and how our own and others' beliefs affect our use of that information.
- **Emotions** - how we feel about ourselves and our intimate relationships
- **Behaviours** - what we do sexually
(Fifield & Esmail, 2000)



Issues Related to Sexuality that Service Providers May Need to Deal With

- Basic Sexual Health Education
- Boundaries appropriate / inappropriate touching
- Safe Sex
- Masturbation education
- Boundaries / permission - promiscuous sexual behavior
- Two kinds of common social mistakes: public vs. private errors.
- Exposing behavior
- Compulsive sexual behavior
- Voyeuristic behavior
- Issues around cognitive competence and consent
- Sexual orientation