

Safety Issues: FASD and Sexuality

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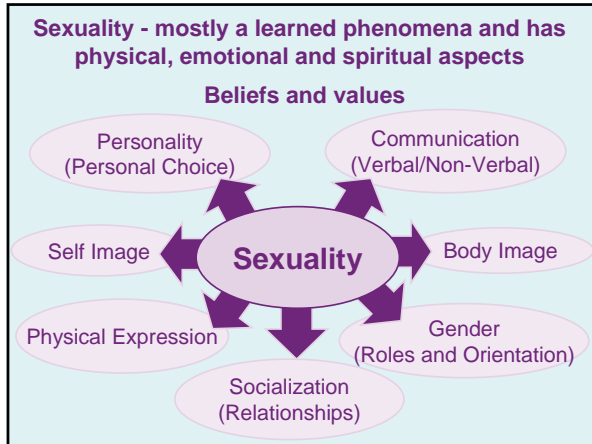
Government of Alberta

The FASD Learning Series is part of the Alberta government's commitment to programs and services for people affected by FASD and those who support them.

Introduction to Sexuality

- Beliefs and Values
- Sexual Health
- Basic Assumptions

SEXUALITY: *The whole person including sexual thoughts, experiences, learnings, ideas, values and imaginings*



Sexual Health

- Is a state of well-being related to sexuality
 - Physical
 - Emotional
 - Mental
 - Social
- It is not merely the absence of disease, dysfunction or infirmity

(World Health Organization Homepage, 2004)

Sexual Health

- Sexual health requires
 - A positive and respectful approach to sexuality and sexual relationships
 - 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

(World Health Organization Homepage, 2004)

Basic Assumptions about Sexuality and Individuals with Disabilities

- All persons, regardless of disability, are sexual persons
- The person with a disability has the right to all information about sexuality that he/she can understand
 - Including the right to full range of sexual expression

Basic Assumptions about Sexuality and Individuals with Disabilities

- The person with a disability has the right to
 - develop relationships with others, and
 - express affection and sexualityin the same ways that are acceptable to others

More Information on FASD Can Be Found on the FASD-CMC Website

<http://www.fasd-cmc.alberta.ca/home/572.cfm>

- FASD 101: Diagnosis and Support of FASD
- Mental Health Problems in Individuals with Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder
 - FASD and Mental Health Treatment: A Multimodal Approach to Transgenerational Issues

Prenatal Alcohol Exposure and the Brain: Functional Implications

- **Socially inappropriate behavior, as if inebriated**
- **Inability to figure out solutions spontaneously**
- **Inability to control sexual impulses, especially in social situations**
- **Inability to apply consequences from past actions**

(Kellerman, 2008)

Prenatal Alcohol Exposure and the Brain: Functional Implications

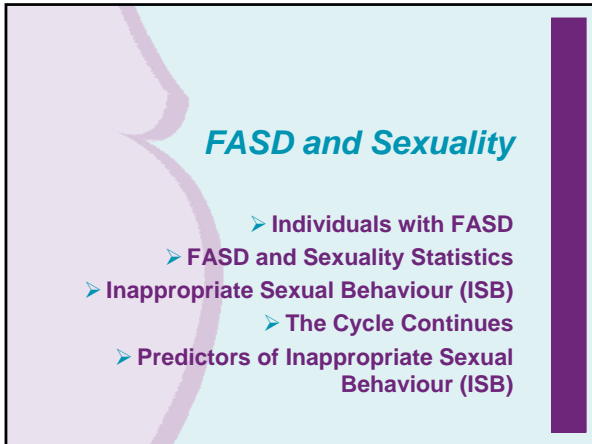
- **Difficulty with abstract concepts or time and money**
- **Difficulty processing information**
- **Storing and/or retrieving information**
- **Needs frequent cues, requires policing by others**
- **Needs to talk to self out loud, needs feedback**

(Kellerman, 2008)

Prenatal Alcohol Exposure and the Brain: Functional Implications

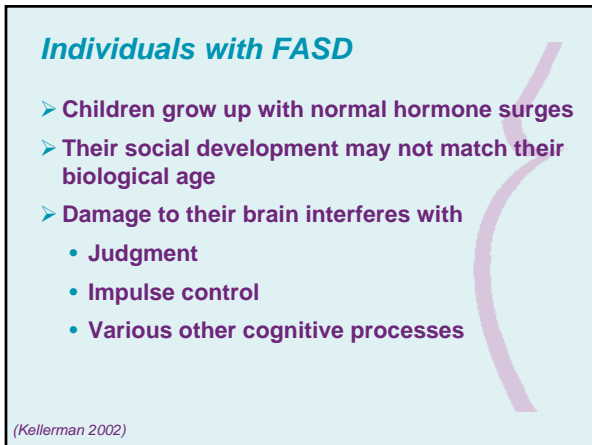
- **Fine motor skills more affected than gross motor**
- **Moody roller-coaster emotions, exaggerated**
- **Apparent lack of remorse, need external motivators**
- **Inability to weigh pros and cons when making decisions**

(Kellerman, 2008)



FASD and Sexuality

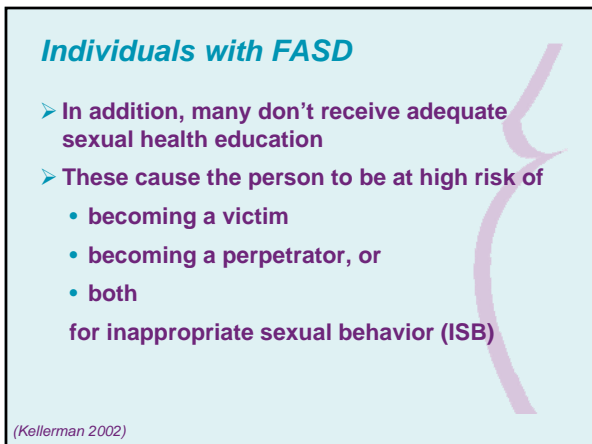
- Individuals with FASD
 - FASD and Sexuality Statistics
- Inappropriate Sexual Behaviour (ISB)
 - The Cycle Continues
- Predictors of Inappropriate Sexual Behaviour (ISB)



Individuals with FASD

- Children grow up with normal hormone surges
- Their social development may not match their biological age
- Damage to their brain interferes with
 - Judgment
 - Impulse control
 - Various other cognitive processes

(Kellerman 2002)



Individuals with FASD

- In addition, many don't receive adequate sexual health education
- These cause the person to be at high risk of
 - becoming a victim
 - becoming a perpetrator, or
 - bothfor inappropriate sexual behavior (ISB)

(Kellerman 2002)

FASD and Sexuality Statistics

- Mean age of onset of inappropriate sexual behavior (ISB) was 9.6 (Streissguth, et al. 2004)
- 39% of the children demonstrated inappropriate sexual behaviour (ISB) (Rasmussen et al. 2007)
- 49% of adolescents and adults had repeatedly displayed inappropriate sexual behavior (ISB) (Blaumbach, 2002, Streissguth, et al. 2004)

FASD and Sexuality Statistics

- 50% of individuals with FASD had repeated problems with inappropriate sexual behavior (ISB) (Kellerman, 2002)
- 77% of individuals with FASD had experienced physical and/or sexual abuse (Clark et al 2004)

Inappropriate Sexual Behaviour (ISB)

Inappropriate as determined by society

- Boundaries - making inappropriate sexual advances
- Inappropriate sexual touching
- Promiscuous sexual behavior
- Exposing behavior
- Compulsive sexual behavior
- Making obscene phone calls

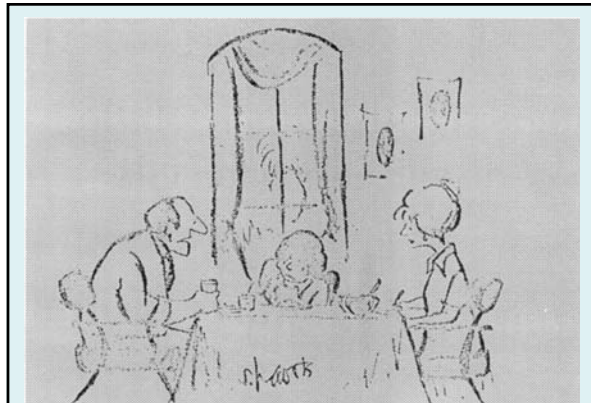
(Streissguth, et al. 2004)

Inappropriate Sexual Behaviour (ISB)

Inappropriate as determined by society

- **Voyeuristic behavior**
 - Peeping
- **Masturbating in public**
- **Incest behavior**
- **Unusual or worrisome sexual behavior**
 - Deviant
 - Paraphilic behaviours

(Streissguth, et al. 2004)



“Yes Billy, masturbation is normal, but not during dinner.”

Inappropriate Sexual Behaviour (ISB)

- **Occurs throughout the lifespan and increasing slightly with age**
 - from 39% in children
 - to 48% in adolescents
 - and to 52% in adults

(Streissguth, et al. 2004)

Inappropriate Sexual Behaviour (ISB)

- Among children, the most frequently mentioned repeated inappropriate sexual behaviors are
 - Exposing (20%)
 - Inappropriate sexual touching (19%)
- Among adolescents and adults, those most frequently mentioned are
 - Promiscuity (26%)
 - Inappropriate sexual advances (18%)

(Streissguth, et al. 2004)

Inappropriate Sexual Behaviour for Males and Females

Similar frequency rate of ISB reported for males and females

However, for females ISB tends to be around promiscuity

While males were likely to get in trouble with the law for ISB

- More coercive
- Nonconsensual activities

(Streissguth, et al. 2004)

Inappropriate Sexual Behaviour for Males and Females

- Females were more likely to be victims of sexual abuse
- Males were more likely to be the perpetrators

(Streissguth, et al. 2004)

I am worried about my oldest daughter, not in the sense that she will be acting out, but that she will be very easily persuaded herself

She is now 12, very attractive and physically mature although socially and emotionally very immature and going into high school in the fall

Father of child with FASD

The Cycle Continues

- **Inappropriate sexual behaviour (ISB) is most often reported for teen and adult females, put them at risk of:**
- **Unplanned pregnancies**
 - **Promiscuity**
 - **Inappropriate sexual advances**
 - **Increased odds of alcohol/drug problems**
 - **Increased chances of females with FASD producing additional alcohol-affected children**

(Kellerman 2002)

The Cycle Continues

In a sample of 100 adult females

- **30% had given birth**
- **40% drank during pregnancy**
- **More than half (50%) no longer had the child in their care**
- **Of their children, 30% have been diagnosed with, or are suspected of having FASD**

(Kellerman 2002)

Predictors of ISB

- Being a victim of sexual, physical abuse or violence has been found to increase the odds for Inappropriate Sexual Behaviour (ISB)
- 94% of the females in their study who had ISB also had experienced sexual abuse, physical abuse or violence against themselves
- A stable/nurturing home is the most influential protective factor reducing by three or four fold the risk of ISB in children and adults

(Streissguth, et al. 2004)

Sexual Health Approaches

- Sexuality As a Human Right
- Approach: Medical vs Sex Positive
- Why Service Providers / Parents Do Not Address Sexual Issues
- Parents Need Support and Reassurance

We live under an Attitudinal Umbrella



of reproductive bias regarding
sexuality

Sexuality As a Human Right

- Historically individuals with cognitive or developmental disabilities have been portrayed as
 - Sexually threatening
 - Requiring professional management and control

(Steele & Cato 1989)

Sexuality As a Human Right

Paradigm shift

Early philosophy

- Any form of sexual expression should be eliminated

Later philosophy

- Sexual expression accepted however believed that control and responsibility should be emphasized

The third viewpoint

- Sexuality and sexual gratification are major life resources and these individuals need to be taught

(Steele & Cato 1989)

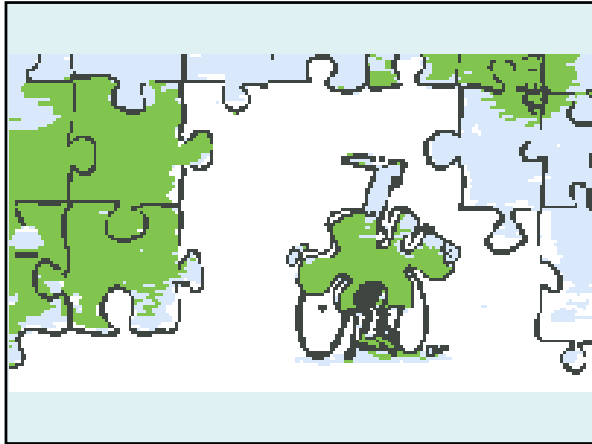
Approach: Medical vs Sex Positive

Medical

- Harm reduction
- Prevention
- Protection

Sex Positive

- Quality of life
- Enhancement



Sex Positive Approach

- “Having a comprehensive definition of sexuality”
- “Viewing sexual health as a basic human right”
- Focusing on both the life-enhancing aspects of sexuality, as well as the negative
- “Being non-judgmental and challenging narrow social constructs”, such as the myth that “sex = intercourse”

Tobin (1997)

Sex Positive Approach

- “Using inclusive language rather than value-laden language which makes assumptions based on sexual orientation or gender stereotypes”
- “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”

Tobin (1997)

Why Service Providers / Parents Do Not Address Sexual Issues?

- Lack knowledge about sexual issues
- Are ill-equipped to deal with sexual issues
- Do not know how to initiate discussions of sex
- Feel uncomfortable in discussing sexual issues
- Do not consider it important as related to other issues
- Do not consider it their role

(Jones, Weerakoon & Pynor 2005)

Parents Need Support and Reassurance

- Almost all of the parents confided that their child with FASD had exhibited inappropriate sexual behaviors
- They were reluctant to discuss this with helping professionals due to fear of the consequences of this being known or their child being labeled on their record

(Kellerman, 2002)

Response by a Mother to Another

12-year-old Son with FASD & ISB

These were posted on the internet. What are your thoughts?

- Put alarms on his door and windows so you can track his movements at night. Don't expect him to have the natural boundaries that most people have for appropriate behavior
- Protect him from crude, vulgar, criminal and sexualized people, behavior, language and visuals
- Don't relax supervision and structure just because he's reached a certain age

Barriers to Sexual Expression

- Individual Barriers
- Attitudinal Barriers
- Structural Barriers

Individual Barriers

- Histories of abuse and trauma
- Lack of self-confidence and esteem that impairs their ability for intimacy
- Medication side-effects can diminish sexual performance and desire
- Certain symptoms (poor social development) inhibit ability to form relationships

Individual Barriers

- Lack of ability to comprehend / need for emotional intimacy but still has physical drive
- Past indoctrination that sexual expression is bad, inappropriate and will be punished

Attitudinal Barriers

- Parents, staff, and service providers often have attitudes and practices that deny the right to a healthy sexual expression
- Parents of adolescents with physical, developmental and/or intellectual diagnosis(es) are less likely to allow their children to associate with peers outside of school hours than parents of their non-disabled peers (1)
- More likely to have limited circle of friends and social contracts (2)

(1) (Zetlin Murtaugh 1988)

(2)(Krauss et al 1992)

Attitudinal Barriers

- Individuals living with such disabilities often acquire sexual knowledge, experience and feelings from different sources and their nondisabled peers (1)
- They are more likely to receive their sexual knowledge from formal education programs and the media not from variety of sources such as peers, parents, social experience
- The whole topic of sexuality is less likely to be normalized because it is not discussed (1)

(1) (McCabe, 1999)

Structural Barriers

- Organizational and institutional policies prevent sexual expression
- Social isolation and overprotection may inhibit their development (sexual and social) (1)
- Opportunities to interact with others tend to be functional rather than opportunities for individuals to form meaningful personal relationships (2)

(1) (Betz, 1994)

(2) (Nunkoosing et al, 1997)

Structural Barriers

- Individuals in segregated settings may be denied the opportunity to form intimate relationships and enjoy little or no time to see or visit with friends outside of institutional settings
- Adults living in the community frequently have their living arrangements chosen and controlled by an agency or guardian. This process often results in people sharing a room with someone they don't like or being denied the opportunity to see friends or possible partners

Structural Barriers

- Additionally, families or agencies may intentionally try to keep them from participating in intimate relationships

(Ailey et al., 2003)

Sexual Health Intervention

- Importance of Sexual Health Intervention
 - Two Inter-Related Issues
 - Self Control
- What Interventions Are Going to Work?

Importance of Sexual Health Intervention

- Sexuality plays a major role in an individual's overall self identity (1)
- Developing a healthy sexual identity requires the opportunity to make decisions to control one's life and build relationships with others (1)
- To engage in fulfilling sexual relationships, people must experience a range of feelings and emotions, develop a sense of self, and feel safe within their environment (2)

(1) Ailey et al., 2003

(2) Downs & Craft 1996; Ailey et al., 2003

Two Inter-Related Issues

- Cognitive deficits
 - Impulsivity
 - Lack of ability to delay gratification
- These put the person at a higher risk for further Inappropriate Sexual Behaviour (ISB)
- Improvement in cognitive function will improve the person's capacity to benefit from treatment

AND

- Sexually inappropriate behavior

Baumbach, 2002

Self Control

- Deficits in response inhibition imply limitations in the capacity for self control (1)
- Learning self-control is central to dealing with inappropriate sexual behaviour (ISB) (1)

But what if there is neuropsychologically a limited capacity for self-control?

- Impact of external cues to help control certain behaviors

(1) (Ryan & Lane, 1997)

My son acts out sexually most when he is overstressed, overtired or I'm gone.

He can quote the rules, knows them all, will tell you afterwards what he did wrong, but it still doesn't stop him.

We are in "mom enforced lock down," and he does know why, but it doesn't make it any easier for any of us.

Cathy

What Interventions Are Going to Work?

➤ So far as treatment for persons with FASD is concerned, in 1996, Weinberg and Guerri wrote that there were no interventions for individuals with FASD of any age that had been scientifically validated

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

J. Potter

Strategies for Dealing with Inappropriate Sexual Behaviour (ISB)

- Strategies for Dealing with Inappropriate Sexual Behaviour (ISB)
- Helping Individuals with FASD Express Their Sexuality Appropriately

Strategies for Dealing with Sexually Inappropriate Behaviour (ISB)

- General treatment recommendations found in the literature seem to have their basis in common sense
- Interventions should be concrete and redundant, with lots of time for practice and repetition ⁽¹⁾
- However Mattson et al.'s (1996) found persons with FASD failed to benefit from repeated exposure to verbal material over five acquisition trials, showing most of their improvement in the first two trials

(1) (Tonneato 1997, as cited in Boland et al., 1998)

Strategies for Dealing with Sexually Inappropriate Behaviour (ISB)

- Assess overall functioning to ensure unidentified impairments will not hamper treatment as well as allow intervention to be designed based on the individuals strengths and limitations
- Medication management
 - Not always the last resort
 - May actually increase person's capacity to benefit from treatment

Strategies for Dealing with Sexually Inappropriate Behaviour (ISB)

- Strategies must be SMART
 - Specific
 - Measurable
 - Attainable
 - Relevant
 - Time based
- Re-evaluate strategies progress regularly

Helping Individuals with FASD Express Their Sexuality Appropriately

- 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 men and women are usually different

Helping Individuals with FASD Express Their Sexuality Appropriately

- Become aware of your own comfort/ discomfort zones
- Find strategies that work for you
- Sexual Health education is the key!!!

Sexual Education

- Sexual Education
- Areas That Need to Be Addressed
- Sexual Education Guidelines for Level and Approach
- Sexual Education and Suggestions for Practice
- Specific Safety Education and Treatment Programs

Sexuality Education

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)

Areas That Need to Be Addressed

<ul style="list-style-type: none"> ➤ Rights and responsibilities of sexual behavior ➤ Dealing with current relationships ➤ Sexual interactions and behaviors ➤ Social skills <ul style="list-style-type: none"> • Assertiveness/the right to refuse ➤ Orientation ➤ Body part identification 	<ul style="list-style-type: none"> ➤ Pregnancy, childbirth and abortion ➤ Sexually transmitted infections ➤ Contraception strategies ➤ Masturbation ➤ Sexual abuse ➤ Personal care and hygiene ➤ Pubertal changes/ menstruation ➤ Medical examinations
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(Ailey et al., 2003 L.; Sweeney, 2007)

Sexual Education Guidelines for Level and Approach

- 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

(Maurer, 2007)

Sexual Education Guidelines for Level and Approach

- 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)

Sexual Education and Suggestions for Practice

- 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

(Maurer, 2007; APA, 1996)

Sexual Education and Suggestions for Practice

- Teach the difference between acceptable behaviors in a private setting and those acceptable in public
- Teach their right to refuse to be touched
- Two kinds of common social mistakes
 - Public-private errors
 - Stranger-friend errors
- Discuss pleasure and affection when educating about sex

(American Academy of Pediatrics, 1996)

Sexual Education and Suggestions for Practice

- Masturbation acceptance / training shown to decrease tension and inappropriate behavior ⁽¹⁾
- Acceptance of the limitations in achieving sexual fulfillment, add to their strength of character and to their having a positive attitude ⁽²⁾

(1) (Thompson,1994)

(2) (Guest, 2000)

Specific Safety Education and Treatment Programs

- Information on safe sex / sexually transmitted infections (STIs)
 - HIV / AIDS
- Techniques for managing high risk situations
- Communication and assertiveness training
- Skill building
 - Demonstrations on condom use

Specific Safety Education and Treatment Programs

- Teaching clients to develop personal awareness of their own high risk situations
 - Role playing
 - Behavioural rehearsal
 - Modeling

Consensual Ability

- Consensual Ability
 - Graduated / Situational Consent
 - Competency to Make Decisions Is Highly Contextual
 - Inability to Give Consent

“CONSENSUAL ABILITY” =
Capability to give informed consent to sexual contact

Consensual Ability

- 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
 - Possible consequences
 - Social and moral context in which it occurs

Consensual Ability

- 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

"Sex drive may not match intellectual capabilities"

Consensual Ability

The ability to give consent is strongly related to

- Sexual knowledge
- Level of intellectual ability
- Social adaptive age
- Participation in sex education course

(Niederbuhl & Morris 1993)

Graduated / Situational Consent

- Able to give consent to some forms of sexual activity that did not include, for example, sexual intercourse which will
 - Protect 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)

Competency to Make Decisions Is Highly Contextual

- Bonnie (1992) argues that a person may be competent to make certain decisions but incapable of making others, even within the same situation
- The “situational competency” allows arguments 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

Bonnie(1992)

Competency to Make Decisions Is Highly Contextual

- 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

(AAP, 1996)

Inability to Give Consent

- A major issue is that 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
- Situational capability is one way of addressing this as it has the potential of striking a balance between enhancing individuals self expression, while ensuring that individuals served are not being exposed in the risk

(Kaeser, 1992)

Inability to Give Consent

If individuals show by their behavior that they wish to engage in certain forms of sexual contact

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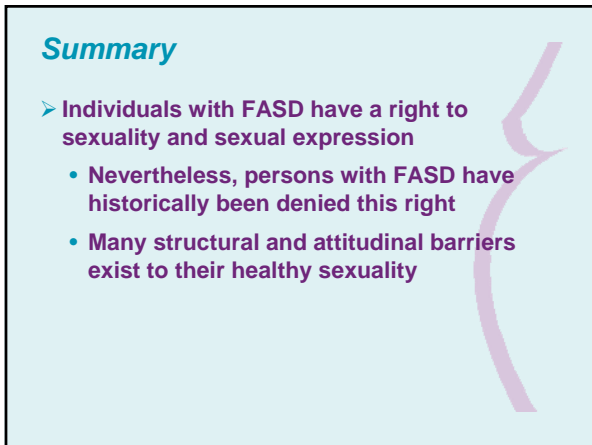
and if the treatment team judges that this contract can improve quality of individuals lives

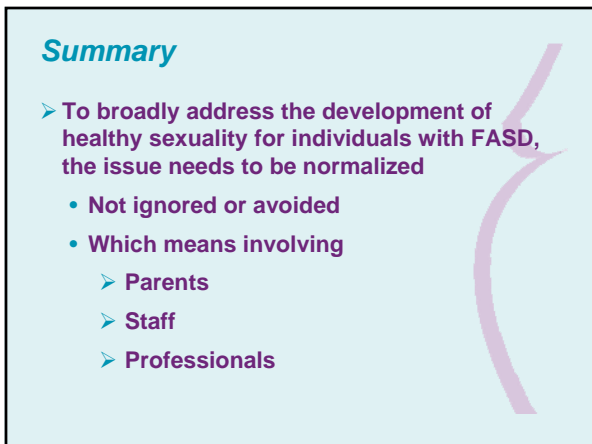
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then third-party consent should be sought, the same as it is in other matters judged to be in the person's best interest

(Kaeser, 1992)









How Do You Incorporate Sexuality into Every Day Practice?

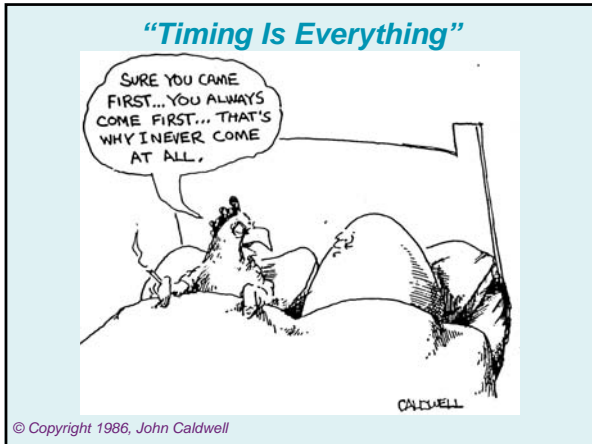
Strategies: Personal and Environmental

- Formal process in place to ensure sexuality is addressed
- Increase self awareness
- Develop knowledge base
- Secure a common ground

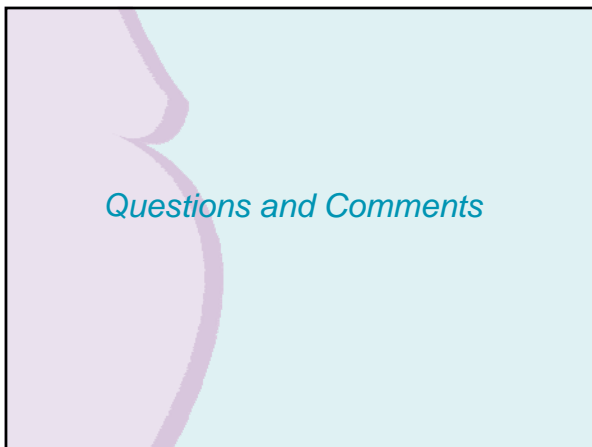
How Do You Incorporate Sexuality into Every Day Practice?

Strategies: Personal and Environmental (cont.)

- Establish a conducive sex positive environment
- Privacy
- Develop an ethical code
 - Dignity
 - Equality
 - Variety of patterns of choice







Contact Information

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