Talking about Sex and Sexuality with Persons with Developmental Disabilities

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Emphasis of This Morning’s Presentation:
Understand, Confront, Prepare and Support
• Understanding the sexuality issues in those with a cognitive disability, cerebral palsy, or an autism spectrum disorder
• Family help in promoting sexual development, growth and maturation in children and young adults with disabilities
• Confronting the risks for sexual abuse: taking measures to help prevent it and knowing what to do if it is suspected

Outline for This Morning:
I. Sexuality and Developmental Disabilities: Close your eyes but it won’t go away
II. The Family’s Role: Promoting Healthy and Fulfilling Sexual Development
III. Recognizing, Preventing and Treating Sexual Abuse

I. Sexuality and Developmental Disabilities: Close your eyes but it won’t go away
What Elephant?
The Elephant in the Room

• Most adults with developmental disabilities (ASD, CP or MR) receive little or no guidance.
• Social skills training rarely teaches how to begin a sexual relationship or how to survive its demise.
• Sexual needs/problems are ignored by the primary physician and a medical specialist won’t be consulted in a timely fashion.
• Those with disabilities are at a great risk for sexual abuse.

Prejudice is Everywhere

• Studies show that sexual behaviors by those with a developmental disability create discomfort in others who do not express their disapproval when similar individuals without a disability are engaged in these very same behaviors.
• This includes both public displays (kissing and touching) and private activities (masturbation and intercourse).

Sexual Perceptions of Caregivers ≠ Reports from Persons with Developmental Disabilities

• Caregivers perceive they support sexual behaviors in their consumers—not so!
• Caregivers perceive they take sexual histories and elicit the identification of sexual problems—not so say our consumers!
• Caregivers perceive that the sexual needs of those with developmental disabilities are different then in those without handicapping conditions—according to consumer surveys, this too is just not so!

So, Who’s Minding the Store?

Some Research on “Staff Behavior and Sexuality Issues”

• Untrained staff and not professional sex educators are the rule-setters/instructors.
• Most often the staff relies on personal values and not a detailed agency policy.
• Personnel changes prevent their being a mentor who helps guide sexual behaviors.
• Staff remains confused about “consent”.
Adding to the Confusion:
Males and Females have different realities

- Sex education is left to the peer group; females talk less and caregivers avoid discussions
- Males with developmental disabilities know more about masturbation, dating relationships, bisexuality and homosexuality
- Males are more open to sex education and frank discussion; females are more guarded and learn to “turn away”

III. The Family: Promoting Healthy and Fulfilling Sexual Development

There’s No Place Like Home for the Education of One and All

Studies Involving Sex Education

- Rates of masturbation are similar in those with developmental disabilities (and motor ability) compared to others
- Parents of children with and without developmental disabilities face a tough task as adolescents develop and mature
- Sex education is for all populations, but a disability demands a tailored approach
- Sex education is the key part of the defense against abuse

Acknowledge that Elephant!

From the American Academy of Pediatrics Committee on Children with Disabilities:

- Teach children and adolescents to express affection in a manner appropriate for their chronological age, not their developmental age
- Behaviors should conform to family standards
- Some things, like hugging strangers, are always inappropriate and “off limits”
- Teach the difference: Public vs Private behaviors
- Teach awareness and how to halt anything that is inappropriate
- Sex Ed is much more than choosing between intercourse or abstinence
SIECUS: the Sexuality Information and Education Council of the United States

- Educational support must be consistent (in the home residence, in school and in day programs).
- Support “is based on the understanding that people with developmental disabilities have the same feelings, needs and desires as those who have no impairments.”

Some Basic Educational Topics Enumerated by SIECUS and Many Others

- Understanding one’s own body, puberty and the development of sexual pleasure
- Understanding gender differences, social relationships and human reproduction
- Discussing the touching and stimulation of “private parts” of the body (masturbation)
- Discussing “privacy” and “propriety”

Why Sex Education is So Important

- Knowledge replaces peer group and internet misinformation and misdirection
- Improves assertiveness and social skills
- Promotes independence; grow-up rather than just grow older for an improved quality of life
- Promotes accountability and responsibility
- Lessens the risk of abuse and molestation
- Reduces the risk of unwanted pregnancy
- Reduces the risk of STDs
- Promotes healthy choices and less risk taking

When to Begin: Sex Education for Children

- An educational foundation in childhood paves the way for advanced learning
- Children use boyfriend and girlfriend to mean “special friend,” or a friend to hold hands with and maybe give a hug
- There’s no need to reinvent the wheel; educational programs for children with developmental disabilities are readily available from many sources
Some Facts of Life for All Families

• Curiosity about sex is normal
• Parental discomfort is normal
• Learning and using correct language is very important
• Awkwardness and opposition will occur
• Being positive and supportive is best
• A multimedia approach is beneficial
• Everything must be along family values

So What Does Your Family Believe?
In regards to:

• Male—female similarities and differences (any double standards?)
• Attractiveness and desirability
• The basis of a good relationship
• Right and wrong ways to be affectionate
• Family rules about disclosing information about dating, about preferences, etc.
• Responsibilities of dependent children

Specific Family Strategies that Work

• Raise young children with roles, tasks and expectations that promote accountability
• Learned helplessness is the fertilizer for future abuse and disappointment
• Start talking about “body parts” and “boys and girls” very early in childhood; NEVER wait until puberty. N-E-V-E-R
• Pick a time and twice a week commit to talk-and-do sessions; get a workbook

Ages 4-10 Topics

• Alike and different—boys and girls
• Different attitudes and different preferences—vanilla or chocolate or…?
• Learning what our family calls right and wrong, and resisting pushes to go wrong
• Childhood behavior may be inappropriate rather than bad (and shameful); even during infancy, inappropriate body behavior needs to be redirected and not labeled
Two Examples of Personal Safety Education

- The “good touch/bad touch model”
  Most dogs sure know the difference and so do kittens and some birds, but all bees just say no!
- The Circles Concept (or Circles Program) teaches how physical intimacy (touching) is related to socially described boundaries that define the relationship

“Safety First” then comes “Sex Education”

Circles also adapts to different ages and levels of cognitive/social adaptive functioning

Ages 10-14

- Changes in a growing body; boys become men, and girls become women
- Heightened sensations, erogenous zones and private versus public touching
- Rules of the road, inside and outside the home; clothing is a good example
- Touch: Where on me and where in the house; private places (for example, the bedroom/bathroom) versus public areas
• Understand the family values and faith beliefs in your home, and then live by them through example and discourse.
• Time and place are everything; the wrong time and/or the wrong place can have terrible consequences for the individual and the family.

May is Masturbation Month

Ages 15-20 to.....
• Relationships and respecting boundaries of talk, touch and trust
• Self-esteem and how to build it up and what can take it away and bring us down
• Self-care and hygiene for adults
• Social skills of acceptance and dealing with the pain of rejection
• Social opportunities to pursue or avoid

Examples of “Advanced Training” for Individuals with a Diagnosis of Autism
• Learn how to listen; being interested in the other person is flirtation’s vitamin
• Good hygiene is a close second
• Share important things, like your hopes, recent experiences, fears and wishes
• Agree to disagree
• The key part of girlfriend is “friend”
• Being hot and bothered can ruin it all
• Social Skills Training and Social Stories

Social Skills Training
• Access and navigation skills: two elements in the most intimate of all social settings, the sexual relationship
• By definition, social skills need two to tango
• A social repertoire requires a sender and a receiver; sexuality skills are essential ingredients on both sides of the equation
• Social demands are sometimes the highest when we engage in sexual relationships
Social Stories

- A key part in the sex education of those with an ASD
- The perspective of the sexual learner or sexually active person is maintained
- All sentences are descriptive, directive, perspective, affirmative, control oriented or cooperative—sounds like sex already
- Social stories in sex education focus on health and hygiene, relationships and self-protection or self-advocacy

Self Advocacy and Sexual Growth

Social stories in sex education focus on health and hygiene, relationships and self-protection or self-advocacy.

The non-profit Human Services Research Institute partnered with self-advocates from around the country to publish The Riot! Newsletter and to offer a number of other great things, like artwork, games, advocacy tools and much more.

http://www.theriotrocks.org/the-riot-newsletter
Some Good Books on Touching

• Sexuality: Your Sons and Daughters with Intellectual Disabilities by Karin Melberg Schwier and Dave Hingsburger

• The Facts of Life... and More: Sexuality and Intimacy for People with Intellectual Disabilities, by Leslie Walker-Hirsch

• Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality (Topics in Down Syndrome), by Terri Couwenhoven

• An Easy Guide for Caring Parents: Sexuality and Socialization: A Book for Parents of People with Mental Handicaps by Lynn McKee and Virginia Blacklidge

• Growing up: A Social and Sexual Education Picture Book for Young People with Mental Retardation by Victoria Shea and Betty Gordon

Touching on the Autism Spectrum

Life and Love: Positive Strategies for Autistic Adults Zosia Zaks

Asperger's Syndrome in Adolescents: Living with the Ups, Downs, and Things In-Between Liane Holliday Willie

Asperger's Syndrome and Sexuality: From Adolescence Through Adulthood Isabelle Henault
IV. Recognizing and Preventing Sexual Abuse

Why an Increased Risk for Sexual Abuse?

- Perception that the disabled individual will not tell, not be believed or valued by others
- Dependency on many others for care
- Lack of education and awareness and have not been taught to just say “no!”
- Learned helplessness and powerlessness
- Vulnerability even when others are around
- Social isolation and “no one to tell”
- No one concerned with the person’s ability for self-protection and self-advocacy

How about the stats?

- Children with disabilities are 3-5 times more likely to be abused than are their peers
- Females are 2-3 times more likely to suffer abuse than males (5-6 times → sexual abuse)
- Women with a developmental disability experience abuse at four times the incidence found in the non-impaired population:
  - 65-70% experienced abuse in their lifetime
  - 50% experienced some form of overt sexual abuse
More Disturbing Numbers

- 75% of women and 50% of men with a developmental disability have experienced some form of molestation by age 18
- Only 3% of offenders/attackers go to jail
- Half the time the molesters return to the scene of their crime, and more often than not, they are in the role of “caregiver”

Inferring Capacity for Sexual Consent when there is mild or moderate ID and/or Autism

- Voluntary: Promoting self-direction
- Safety: Protection of those involved
- No exploitation: No power or status differential and no tangible rewards
- No abuse: Physical or psychological
- Ability to say NO: At any time
- Socially appropriate: Both time and place


Preventing Abuse

- Sex education, sex education and more sex education for consumers and staff BEFORE the horse is out of the barn
- Develop an IRP (Individual Response Plan) for any behavior suspected as abuse or as an attempted sexual assault
- Supervise those who supervise our consumers; constantly conduct surveys or evaluations where consumers talk about their ongoing staff experiences

ESCAPE

An Effective Strategy-based Curriculum for Abuse Prevention and Empowerment (WID, the World Institute for Disability, has a CAPE program, Curriculum on Abuse Prevention and Empowerment)

- Interviews, lectures, videos, role-playing, encounter sessions and more
- Personal safety, decision making, self awareness and empowerment are topics
- Identifying, building and strengthening a support group are skills that are teachable
- Programs that succeed (i.e., lower the rates of abuse) have a curriculum that goes on for years
CAPE: Curriculum on Abuse Prevention and Empowerment

A focus on peer support in abuse prevention, using videos, comics, quizzes, games and true stories:

Sticks and Stones: Disabled People’s Stories of Abuse, Defiance and Resilience

Four parts complete the program:

1. Abuse discussed as part of independent living or relationships with caregivers, and learning self-protection/empowerment
2. Anger management and the needs of specific populations
3. Training Tools on setting up workshops, support groups and public media programs, including PowerPoints, interactive lectures and movies
4. Multimedia tools including games and short educational videos

Treating Abuse and Supporting the Abused

• Teaching what to do in the future (i.e., what wasn’t done before), can be both a burden and a punishment to those weakened and vulnerable by abuse

• Most importantly, “sex education” is not to be confused with the therapy needed after the abuse has occurred

Generic but Also Unique

• Involve a therapist who is familiar with people who have developmental disabilities; establish relationships and refer to these therapists so they are available in crisis situations

• Like in grief reactions, those with an intellectual disability may have a delayed response (i.e., months or years later)
Offering Help or Creating Harm?

- Interaction with a developmentally delayed person is oftentimes directive, suggestive and coercive; there is a high potential for introducing error and limiting the reliability of any reports.
- Care must be taken not to infer shame or hidden secrets when there is silence or unresponsiveness; give the message, “It’s all going to be okay” without having to find out (i.e. fabricate) all of the details.

Size Does Matter

- One size does not fit all when we try to find the best way to help the abused and the best means to treat transgressions.
- One size does not fit all when it comes to the best way to provide sex education.
- One size does not fit all when it concerns the best way to support sexual development and sexual expression and fulfillment in our consumers.

Fit the Expectations to the Person

- Every one of us has a unique sexual reality and the way to enhance the lives of our consumers is to treat each and everyone as the individual they are.
- Tailor the supports to fit the individual!
- Always Promote self advocacy!

Before jumping in, please take the full measure of the situation!

Be prepared to swim against the tide:

Be prepared to fight with with stereotypes:

And be prepared to RIOT!