



Specific Disabilities and their Impact on Sexual Expression

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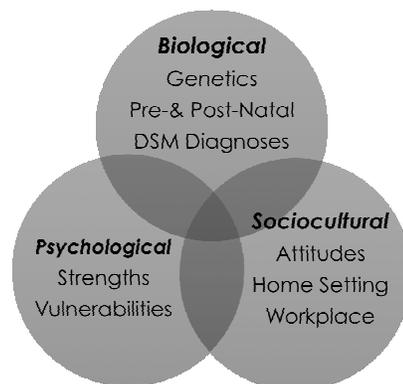
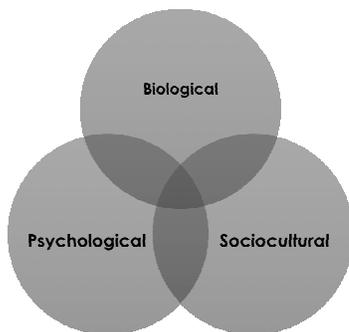
Agenda

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- Context
 - Biopsychosocial Approach
- Brief Descriptions of Specific Disabilities
- Background information on Sexuality and Disability
- Specific Effects of Disabilities on Sexual Expression
- Suggestions for Sex Education, Counselling, and Treatment

Biopsychosocial Approach

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Developmental Disabilities

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Chromosomal Disorders

- Non-sex chromosomes
 - Down syndrome
- Sex chromosomes
 - Fragile x syndrome
 - Klinefelter

Genetic Disorders

- Recessive
 - Lesch-Nyhan syndrome
- Unknown genetic etiology
 - Smith-Magenis syndrome
 - Prader-Willi syndrome
 - William's syndrome

DSM Diagnoses

- Autism Spectrum Disorders

Non-genetic Disorders

- FASD

Down syndrome

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- Trisomy 21
- 1 out of every 700-1000 live births
- Characteristic facial appearance; epicanthal folds; single crease across palm; hypotonia; short stature
- Stereotyped "Down syndrome personality"
- Health problems include:
 - congenital heart defects (50%)
 - hearing loss (66-89%)
 - ophthalmic conditions (strabismus- 60%)
 - hypothyroidism (50-90%)

Fragile X syndrome

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- Most common inherited cause of intellectual disability
- Full mutation appears in approximately 1 in 3600 males and 1 in 4000 to 6000 females
- Mutation on the X chromosome
 - enlarged ears, long face with prominent chin
 - attention deficit disorders
 - speech disturbances
 - hand biting
 - hand flapping
 - autistic behaviour
 - poor eye contact
 - aversion to touch and noise

Klinefelter syndrome

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- First human sex chromosomal abnormality to be reported
- XXY karyotype
- 1 in 500 male births
- Typically have learning difficulties
 - Verbal skills disproportionately affected as compared with nonverbal abilities (Dykens et al., 2000).

Lesch-Nyhan syndrome

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- X-linked recessive disorder
 - Near absence of an enzyme that leads to excessive uric acid production
 - Results in neurological, renal, and muskuloskeletal manifestations
 - Delayed motor development and spasticity
 - No individual with this syndrome has been able to walk or sit without support
- Prevalence is approximately 1 in 200,000
- Behavioural features
 - Extreme self-injury with loss of tissue due to biting

Smith-Magenis syndrome

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- Deletion on Chromosome 17
- 1 in 25, 000 to 1 in 50, 000 live births
- Characteristic face; flat mid-face; broad nasal bridge; fair hair and complexion; large teeth; stork-like gait; self-hug
- Self-injurious behaviours (peripheral neuropathy; polyembolokoilamania);
- Sleep disturbances; attention-seeking ; perseveration; low impulse control

Prader-Willi syndrome

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- Deletion of part of the paternal copy of Chromosome 15q
- Characteristic facial appearance; underdeveloped sexual characteristics; hypopigmentation; hypotonia; small hands & feet; short stature
- Compulsive behaviours; affinity for jigsaw puzzles
- Rapid weight gain between 1 and 6 years old
- Insatiable appetite
- Most medical problems due to obesity

Williams syndrome

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- Continuous deletion on area of chromosome 7
- 1 in 20, 000 live births
- Characteristic face; hyperextensible joints
- Extreme sociability
- High rates of anxiety/fears/phobias
 - 95%- Hyperacusis/hypersensitivity to sound
- Health problems include cardiac problems; hypertension

Asperger's syndrome

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- DSM-IV- PDD classification; part of Autism Spectrum Disorders
 - (1) Social isolation
 - (2) pedantic speech
 - (3) unusual interests that occupy large part of their time
- No significant delay in language development
- Social problems do not manifest until ~ daycare age
- Anxiety towards change

Fetal Alcohol Spectrum Disorder (FASD)

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- New term that encompasses many of the alcohol-related diagnostic categories and highlights the continuum of symptomatology
- Cluster of symptoms that occur together and result from prenatal alcohol exposure
 - Fetal Alcohol Effects (FAE), Possible Fetal Alcohol Syndrome (PFAS), Alcohol Related Birth Defects (ARBD), and Alcohol Related Neurodevelopmental Disorder (ARND)
- 1 to 6 in 1000 live births (Stade et al., 2006).

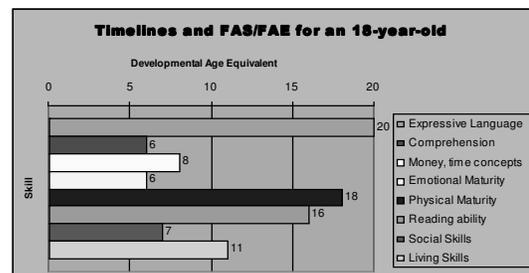
Characteristic Effects of Prenatal Exposure to Alcohol

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1. *Characteristic pattern of facial anomalies*
2. *Evidence of growth retardation:*
 - Low birth weight for gestational age
 - Weight loss over time not due to other causes
 - Disproportional low weight to height
3. *Evidence of brain or central nervous system abnormalities in:*
 - Decreased cranial size at birth
 - Structural brain abnormalities
 - Neurological hard or soft signs (impaired fine motor skills, neurosensory hearing loss, poor tandem gait, etc.)

Fetal Alcohol Spectrum Disorder

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Sexuality and Disability 

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Myths regarding sexuality (Griffiths, 2007) 18

People with developmental disabilities (DD):

- are eternal children and asexual
- need to live in environments that restrict and inhibit their sexuality to protect themselves and others
- should not be provided with sex education as it will only encourage inappropriate behaviour
- should be sterilized because they will give birth to children who are also disabled

Myths regarding sexuality (Griffiths, 2007) 19

- are sexually different than other people and are more likely to develop diverse, unusual, or deviant sexual behaviours
- are over-sexed, promiscuous, sexually indiscriminate, and dangerous, and you have to watch your children around them
- cannot benefit from sexual counselling or treatment

Myths regarding sexuality (Griffiths, 2007) 20

- These myths serve a common purpose: *to push the sexuality of individuals who have a developmental disability outside of the "normal" range*
- As long as these myths exist, the sexuality of individuals who have DD will continue to be misunderstood and misrepresented

Sexuality

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- Sexuality is more than simply sexual behaviour
- Acquired physical and mental impairments may alter one's sexual drives, but they do not eliminate basic sexual drives or human needs for affection, intimacy, as well as a healthy and positive and positive self-concept



The Need for Sex Education

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- Interest that people with DD have expressed in learning more about sexuality
- Individuals who have DD are sexual beings with gaps in knowledge and experience
 - Often sheltered from sexual knowledge and typical experiences that would assist them in developing a healthy understanding of their sexuality
- Negative attitudes toward sex

The Need for Sex Education

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- Deinstitutionalization
- Increased incidence of sexual abuse against people with intellectual disability
- Increasing risk for sexually transmitted infections and HIV infection

Risk for Sexual Abuse

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- Regardless of age, individuals with DD appear to be more vulnerable to abuse than individuals who do not have a disability
 - Although the exact degree of risk varies from study to study, it appears to be at least 150 percent of that for individuals
- Not directly related to the nature of the individual's disability
 - Assumptions many people make about individuals who have developmental disabilities
 - "Sexual abuse is more than a sexual act - It is an expression of power" (Griffiths, 2007, p. 579)

Heightened Vulnerability

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- Limited experience with relationships
- Limited experience with assertiveness and choice making
 - Obedience and compliance
- Social isolation
- Poor communication skills
 - Limited affective and sexual vocabulary

Risk for STI & HIV Infection

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- Among adolescents, individuals who have disabilities appear to be a group potentially at high risk for contracting AIDS
- Thompson (1994)
 - "Cottaging"
- Questions exists about whether mediating variables, such as impulsivity, awareness of disease causality and control, and perception of self-efficacy affect the risk behaviours associated with transmitting STIs and HIV

Inappropriate Behaviour

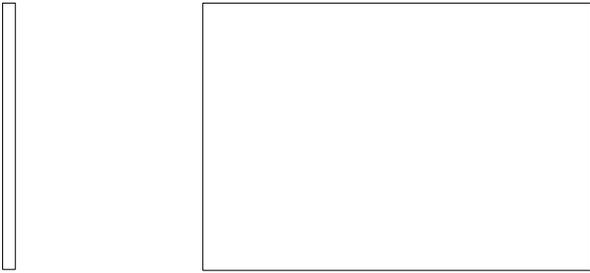
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- Diagnosis?
- Sensory integration difficulties
 - Self-stimulation
- Sexual abuse
 - Modelling
- Poor social skills, poor impulse control
- Lack of outlet for appropriate sexual expression

Counterfeit Deviance

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- Hingsburger, Griffiths, and Quinsey (1991) coined this term to describe the sexual misbehaviour of individuals with disabilities as a product of experiential, environmental, or **medical** factors
- 11 hypotheses
 - Perpetual arousal
 - Medical side effects
 - Inappropriate courtship



The impact of specific disabilities on sexual expression

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Down syndrome

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Biological

- Males, generally sterile (decreased production of sperm)
 - Fertility rate in females is low
- Precocious puberty and menorrhagia (heavy periods)
 - Related to hypothyroidism
 - Early menopause
- Depression and compulsive behaviour quite common

Sexual Expression

- At an increased risk of sexual abuse due to social natures

Fragile X syndrome

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Behavioural

- Great need to please; to be loved
- Impulsivity
 - Sexual frustration; may precipitate aggression

Biological

- Most males develop large testicles (macro-orchidism)
- Epilepsy and Major depression quite common

Sexual Expression

- Aggression, anxiety, and social avoidance may impact their sexual identity and their expression

Klinefelter syndrome

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Biological

- Hypogonadism (sex glands produce little or no hormones)
- Elevated gonadotropic hormones
 - Gynecomastia (breast enlargement in males)
 - Delayed development of secondary sexual characteristics
- Lack of sperm
- Sexual dysfunction
 - Decreased libido

Sexual Expression

- Speak inappropriately
- Esteem issues

Lesch-Nyhan syndrome

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Behavioural

- Extreme self-injury

Biological

- Mobility deficits
- Delayed puberty
- Overproduction of uric acid
 - Vulnerability to urinary tract infections

Sexual Expression

- Self-injurious behaviour is problematic (masturbation)

Smith-Magenis syndrome

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Behavioural

- Polyembolokolomania (orifice stuffing)
- Females: vaginal stuffing- Low impulse control
 - aggressive hugging; bodily self-hugging
 - Smelling or sniffing behaviours

Biological

- Puberty can be difficult for females
- Urinary tract abnormalities

Sexual Expression

- Suspicion of sexual abuse, but actually form of self-injury (stuffing)

Prader-Willi syndrome

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Biological

- Under-developed physical sexual characteristics
 - Hypogonadism;
 - Cryptorchidism
 - Low energy; sex drive
 - Delayed puberty
 - Menarche occurring as late as the 30s
 - Precocious development of pubic and underarm hair

- Seizures quite common
- Obsessive-Compulsive behaviour

Sexual Expression

- Impulse control

Williams syndrome

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Behavioural

- Friendly demeanor
 - no stranger anxiety; impulsivity

Biological

- Menstrual problems
 - Extreme PMS; outbursts of anger during menses
 - Precocious puberty
- Obsessive-Compulsive behaviour

Sexual Expression

- Vulnerable to exploitation
- Inappropriate sexual behaviour due to increased sociability

Asperger's syndrome

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Behavioural

- Self-stimulation

Biological

- Hypersensitivity; *hyposensitivity*

Sexual Expression

- Inappropriate sexual behaviour due to social skills deficits
 - boundaries
 - frustrations

Sex education and counselling for
individuals with disabilities

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What should we teach?

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- When sexuality information is provided, it is frequently to address problems and is not formulated to integrate a person's sexuality into other aspects of the person's life
- Sexuality training is best used *proactively* or *preventatively*
 - The objective of socio-sexual education should be to teach responsibility for one's sexual feelings and desires, not to eliminate sexual interest and response

What should we teach?

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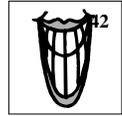
- Basic Body Part Identification
 - Training regarding Pap smears and pelvic examinations
- Relationship Training
- Information regarding STIs and birth control
- Empowerment/Self-Esteem Training
 - Emphasis on sexual choice and sexual responsibility
- Individualized Training

Anatomy and Sexual Health



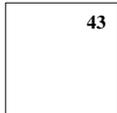
- Anatomy and physiology as well as maturation and body changes
 - Discussion of male and female anatomy, including reproduction, the sexual life cycle, and human sexual response
 - Remain cognizant of the ways a specific disability may affect reproductive ability and physical appearance
- McCarthy (1993; 1996)
 - Teaching about bodies in order to increase sexual pleasure as well as to decrease vulnerabilities

Sexual Pleasure



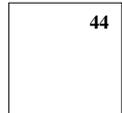
- Most women who have spoken about sexual experiences have said that they do not experience much, if any, sexual pleasure
 - It must be emphasized that physical pleasure is not the only kind of pleasure to be gained from engaging in sex
 - Be certain that sex education includes discussions of the emotional and social aspects of sexuality, not just instruction on the anatomy and mechanics of sexuality

Relationship Training



- What constitutes appropriate and inappropriate sexual relationships
- Responsibilities that come with sexual expression
- Reproduction and sexual behaviour are not synonymous
 - Important social and emotional contexts of sexuality are often carefully withheld from sex education
- For most individuals who have DD, sex is experienced primarily *physically*, rather than as a *psychological* or *emotional* connection with the person concerned

Empowerment/Esteem Training



- Positive sex messages
- Self-esteem
 - Positive body image
- Assertiveness
- Choice
 - Discrimination of appropriate and inappropriate requests

Birth Control/ STIs

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- Individuals should be educated about how it can be prevented and also what should be done if one suspects that he or she may have contracted an STI
- In discussing reproductive options and birth control, one must assess whether the disability influences fertility and fertility options
 - Reproductive choices that are suitable for women who have a disability must be discussed and made available

How Should we Teach Sex Ed?

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- Life-long process
 - Accurate information when it is age-appropriate and contextually relevant for them to know it
 - Good sexuality education should begin at birth, couched in a framework of positive healthy attitudes and responses from nurturing adults

How Should we Teach Sex Ed?

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- Formal sex education classes are largely not effective
- Sexuality needs to be *normalized* among people with disabilities
- Sex education programs have a greater likelihood of success if parents and care staff are also involved, both in terms of exposure to the program and working through the program with the people with intellectual disability

Individualized Training

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- The real challenge is to assist people to gain a sense of sexual identity whether that be as part of a heterosexual or homosexual relationship, or to be a sexual being without a partner
- Must develop a sense of the actual sexual needs and experiences of people with intellectual disabilities
 - Only then can we tailor programs to address needs, rather than imposing the values of people without disabilities on people with disabilities

Individualized Training

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- Programs have tended to assume a heterosexual perspective
- 10% of the North American population has a homosexual orientation, including those who have a DD
- Men with disabilities living both in institutions and community settings are significantly more likely to have had sex with men than with women



Individualized Training

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- Specific Developmental Disabilities
 - Special educators have not traditionally included information about the causes of individuals' disabilities into their everyday work
 - Cause of an individual's developmental disability can impact on his or her learning style, behaviour, and educational needs
- Dykens, Hodapp, & Finucane (2000)
 - "best educational setting"

Individualized Training

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- Down Syndrome
- Fragile X Syndrome
- Prader Willi Syndrome
- Williams Syndrome
- Fetal Alcohol Spectrum Disorder

Down syndrome

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- Difficulties in developing certain language skills, especially in expressive language and grammar
- Perform much better on visual-spatial tasks than on verbal or auditory tasks

Fragile X syndrome

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- Strengths include verbal skills, long-term memory for learned information, and expressive vocabularies
- Do well with integrated tasks that have a visual or hands-on component (pictures, diagrams) or use a familiar context

Prader-Willi syndrome

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- Visual perception strengths
 - affinity for jigsaw puzzles

Williams syndrome

55

- Auditory and verbal strengths
 - Musical strengths
- Distractibility
- Anxiety

FASD

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- Strengths
 - Expressive language
 - Reading ability
- Limitations
 - Comprehension
 - Emotional maturity
 - Social skills
 - Naivety

Sexuality is an integral part of the personality of everyone: man, woman, and child. It is a basic need and an aspect of being human that cannot be separated from other aspects of human life

Questions?

Thank you

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Resources

- Griffiths, D. & King, R. (2004). *Demystifying syndromes: Clinical and educational implications of common syndromes associated with persons with intellectual disabilities*. Kingston, NY: NADD Press.
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- Henault, I. (2006). *Asperger's syndrome and sexuality*. London: Jessica Kingsley.
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- SIECCAN (Sex Information and Education Council of Canada www.sieccan.org)