

# ICCER Networking Event:

## Ethical Dilemmas in Continuing Care

Oct 15<sup>th</sup> 2018



# *Healthy Sexual Expression - "Never Gets Old"*



**Dr. Shaniff Esmail**

**[Shaniff.esmail@ualberta.ca](mailto:Shaniff.esmail@ualberta.ca)**

**Dept of Occupational Therapy**

**Faculty of Rehabilitation Medicine**




# Today's Presentation

- Defining Sexuality
- Sexuality and Aging
- Myths regarding sexuality and aging
- Impact of Aging on Sexuality
- Issues related to Sexuality
- Issue of consent
- Sexuality in Institutions - Barriers
- Defining healthy sexual expression
- Our Role
- Q & A





"I don't know if this is such a wise thing to do, George."

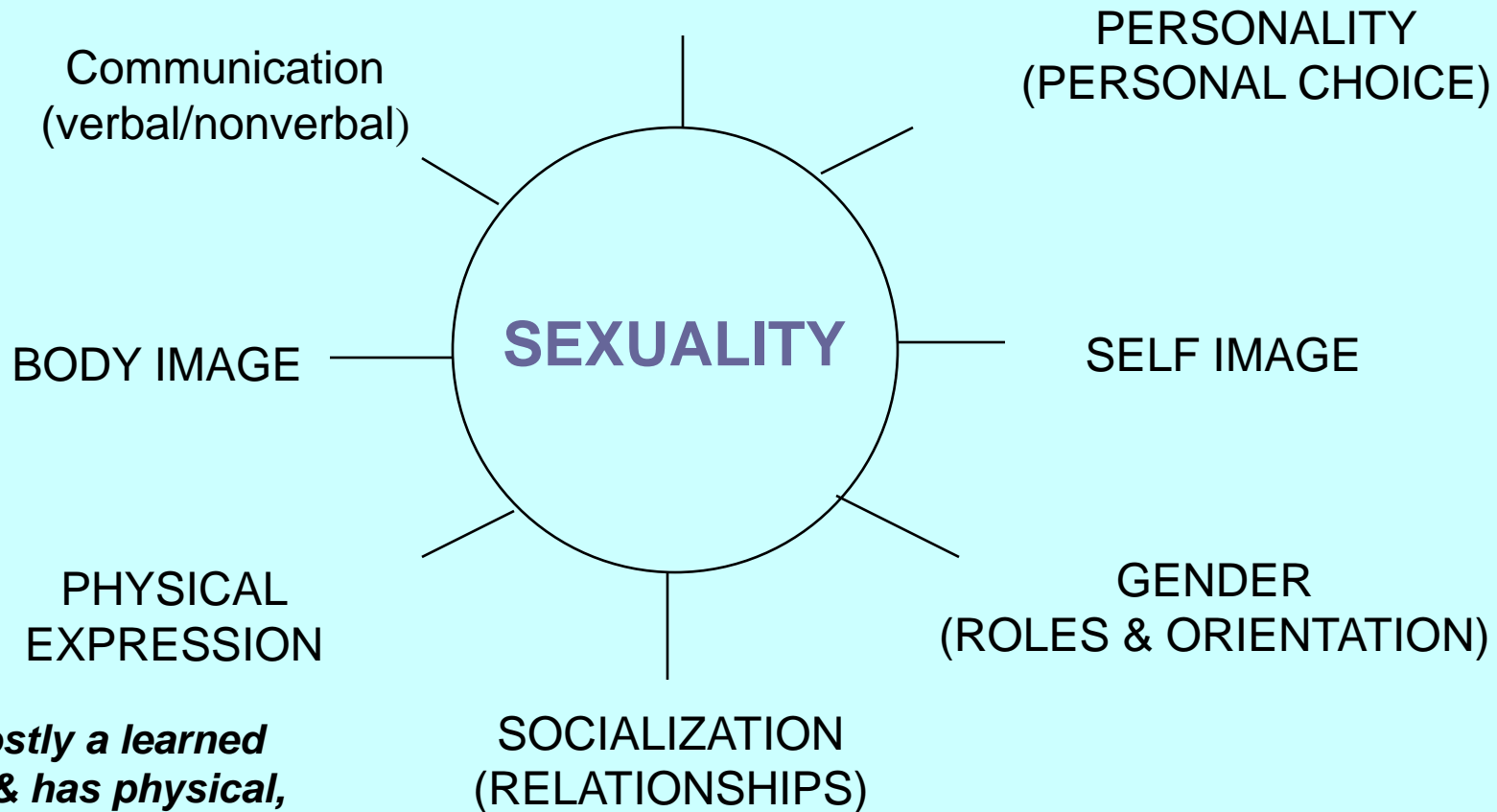


*“Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It’s easier for us to talk about – and formulate strategies for changing – discrimination in employment, education and housing than to talk about our exclusion from sexuality.”*

Anne Finger, *Forbidden Fruit*

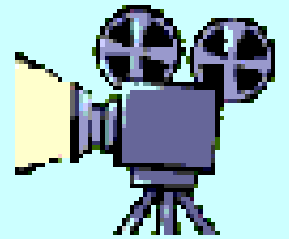
# Sexuality: The whole person including sexual thoughts, experiences, learnings, ideas, values and imaginings

## Beliefs and Values



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

# We live under an Attitudinal Umbrella



of Reproductive bias regarding sexuality



*Majority of older adults are engaged in intimate relationships and regard sexuality as an important part of life*

(Lindau et al 2007)

# Selected Facts

## Sexuality and Aging



- Approximately 70% of healthy 70 year olds continue to have regular sexual intercourse.
- People 65+ are often having as much sex and in some case more than people aged 18-26
- 40% of women and 50% of men in their 60s masturbate
- Research in Sweden revealed that older adults who are sexually active have more vitality and better memories than celibate counterparts.

(Janus Report on Sexual behaviour, 1993; Kaplan, 1990 Global Sexual Health survey 2002)





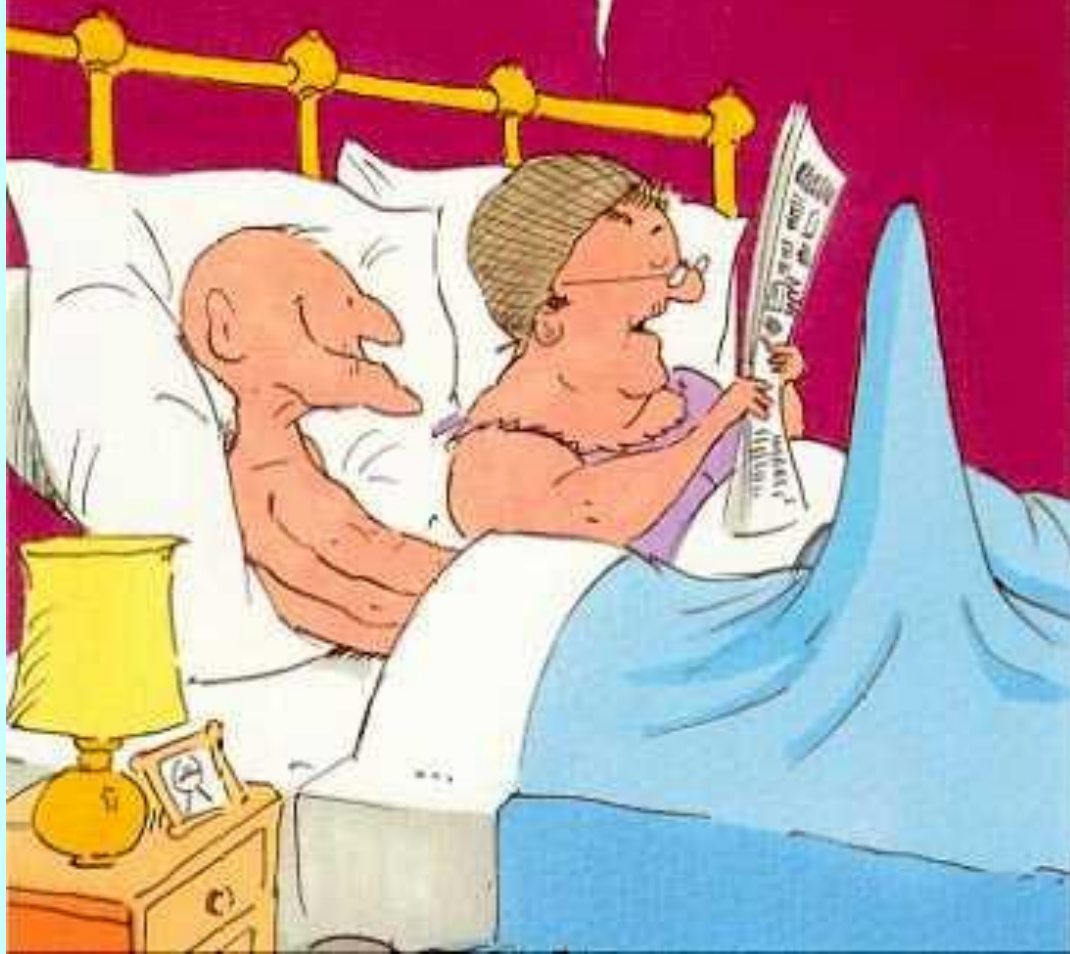
# Selected Facts

## Sexuality and Aging

- 93% of men 65+ frequently have orgasms during intercourse
- 50% of women 65+ frequently have orgasms during intercourse
- More than 25% of healthy older adults 80+ are still sexually active, (avg. frequency of intercourse is 4X month)

(Janus Report on Sexual behaviour, 1993; Kaplan, 1990 Global Sexual Health survey, 2002)

STOP  
SHOWING OFF..I KNOW  
IT'S YOUR WALKING  
STICK



# Aging-Dealing with Loss and its impact on the individual

- Loss of roles
- Loss of partner
- Loss of function/independence
- Disability/illness (physical and cognitive)
- Sexual Identity
  - an expected/accepted loss ?

# The following may be Affected to Varying Degrees:

## **GENERAL ISSUES:**

- Body image
- Self esteem
- Family/public attitudes

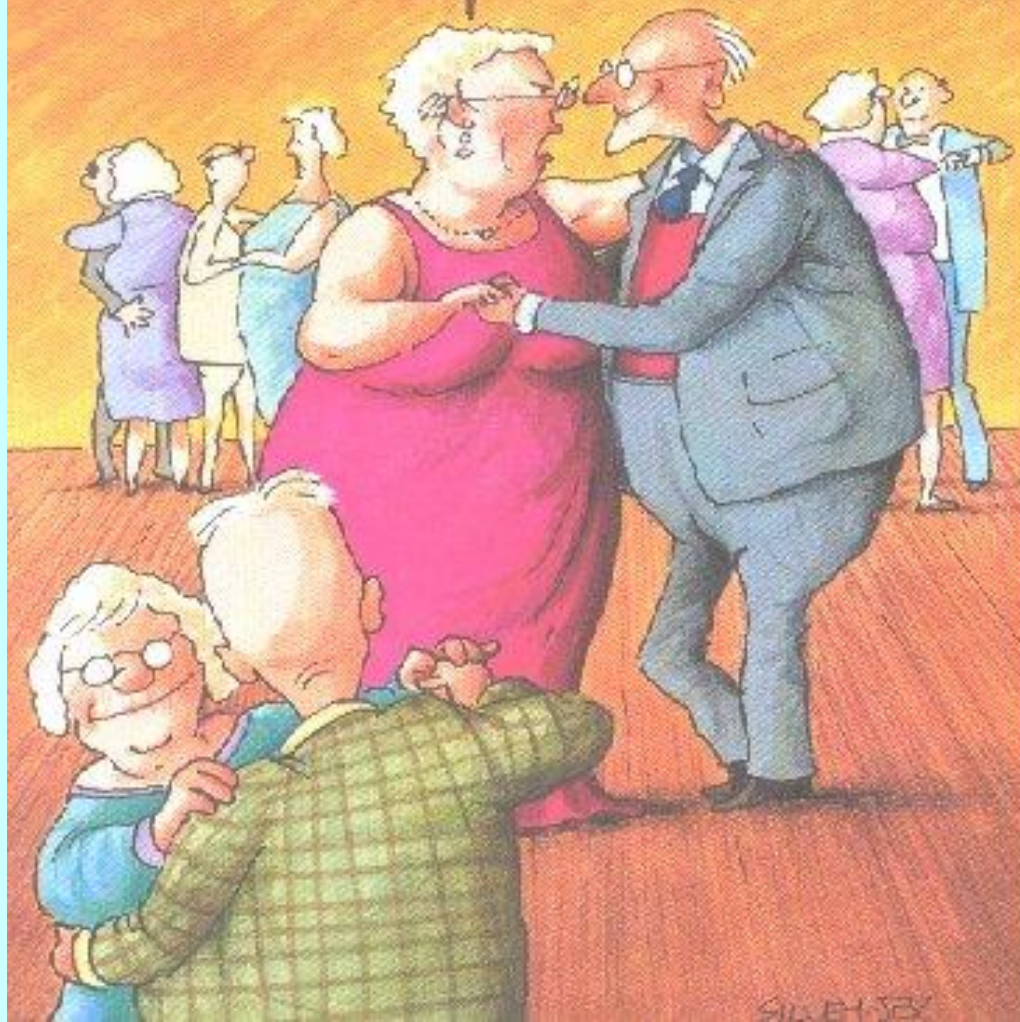
## **REPRODUCTION AND SEXUAL RESPONSES:**

- Fertility
- Arousal – Orgasm – Sexual response

## **CHOICES OF SEXUAL BEHAVIOURS:**

- Opportunity for privacy
- Positions for sexual intercourse and other sexual behaviors
- Availability of partner(s)
- **Intellectual abilities**

NO...NO...  
I SAID I'VE GOT  
ACUTE ANGINA



SILVER

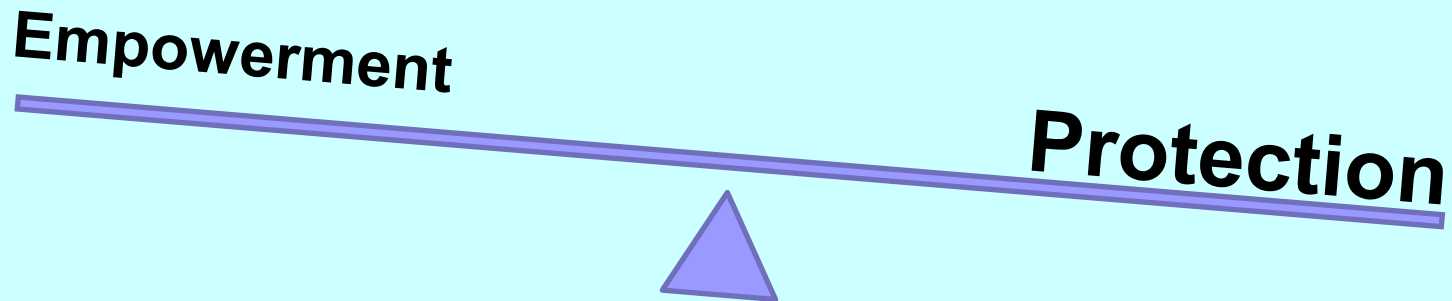
# Issues Related to Sexuality

- Boundaries appropriate / inappropriate touching
- Safe Sex – sexy seniors class
- Masturbation education
- Sexual orientation
- 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

# Disability Dilemma

*For people with intellectual disabilities, there is a difficult balance to be struck between empowering people to claim their sexual rights and protecting them from negative consequences such as abuse, assault, STI's etc.*

(Murphy & O'Callaghan, 2004)



# “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”



# 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 Capacity”** 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)
- The functional approach has been preferred to the diagnostic and outcome approaches to capacity (Grisso & Appelbaum, 1998; Gunn et al., 2001; Murphy & Clare, 2003)



*“the prevailing idea of sexual autonomy assumes the mind to be dominant and controlling, irrespective of ... circumstances.”*

the notion of consent to sexual activity has been constructed from an **ablest** perspective, imposing a standard of normative cognition on consent and construes sexual activity from the perspective of the heteronormative societal perspectives.

(Doyle, 2010)

# Barriers to Sexual Expression

- Chronic illness/disability
- Lack of willing partner
- Feelings of unattractiveness
- Sexual predators (harm reduction)
- Attitudes/Comfort of staff
- R<sup>3</sup> (Rules, regulations and resources)

**HARM REDUCTION VS SEX POSITIVE**

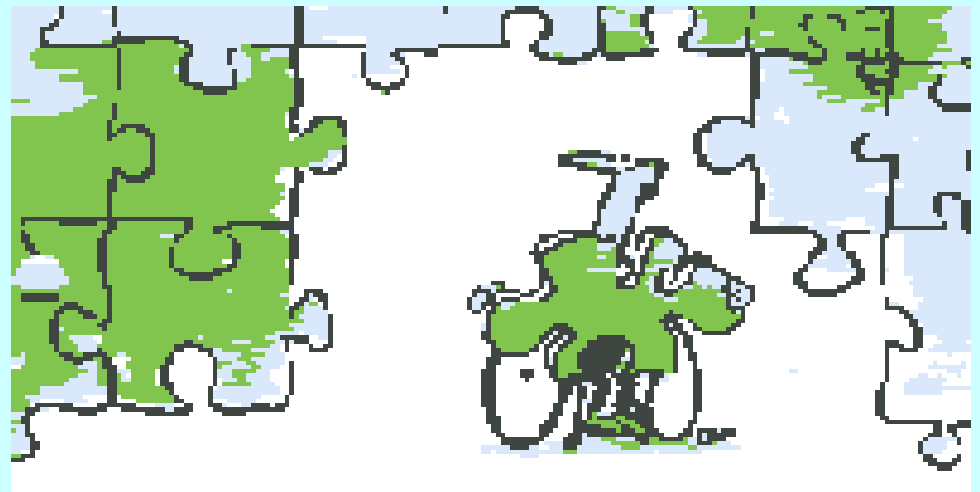
# Approach When Dealing With Sexuality: Medical Vs Sex Positive

## **Harm Reduction:**

Prevention, and protection

## **Sex Positive:**

Quality of life, enhancement



# Harm Reduction

- An approach that gained popularity due to the increased spread of AIDS among injection drug users
- Principles can be applied to engagement in sexual activity by people with Intellectual Impairment
- Features:
  - Pragmatic
  - Value-neutral view
  - Humanistic values – recognizes the autonomy of the individual
  - Focus on decreasing or minimizing negative consequences

(Erickson, Riley, Cheung, & O'Hare, 1997; Inciardi & Harrison, 1999; Riley & O'Hare, 2000)

# Sex Positive Approach

- “Having a comprehensive definition 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”  
(Harden, 2014; Tobin, 1997; Williams, Prior, & Wegner, 2013)

## Benefits

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

## Limitations

- Defining what falls within **healthy sexual expression**
- Individuals’ inability to articulate or even understand person needs
- Service provider’s inability to fully grasp the extent and definition of sexual expression in relation to challenges triggered by disability



# What is Healthy Sexual Expression?

- Take a minute and list some elements you feel should be included in the description of healthy sexual expression

# 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)



# Healthy Sex Vs Harmful Sex

## Healthy Sex

Sex is a choice

Sex is a natural drive

Sex is nurturing, healing

Sex is an expression of love

Sex is sharing with someone, part of who I am

Sex requires communication

Sex is private

Sex is respectful

Sex is honest

Sex is mutual

Sex is intimate

Sex is responsible

Sex is safe

Sex has boundaries

Sex is empowering

Sex enhances who you really are

Sex reflects your values

Sex enhances self esteem

## Sexual Abuse and Addiction

Sex is an obligation

Sex is addictive

Sex is hurtful

Sex is a condition of love or devoid of love

Sex is “doing to” someone

Sex is void of communication

Sex is secretive

Sex is exploitative

Sex is deceitful

Sex benefits one person

Sex is emotionally distant

Sex is irresponsible

Sex is unsafe

Sex has no limits

Sex is power over someone

Sex requires a double life

Sex compromises your values

Sex feels shameful

(McKinley Health Center, 2009)

# Sexual Expression

## Person Centred Program

- Facilitates meaningful life change
- Highest chance for success and application of knowledge, skills, and attitudes
- Team approach
- Tailored specifically to each individual:
  - Degree of intellectual disability
  - Presence of physical disabilities
  - Existing skills and deficits
  - Individual goals



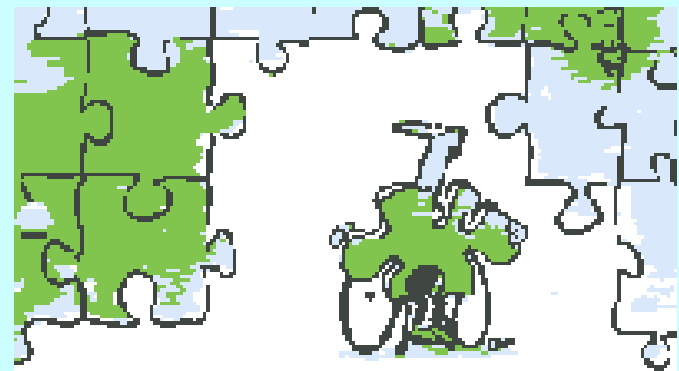
# Advantages to Person Centred Team

- Involvement of persons who work closely with the target individual should improve the likelihood that developed programs will fit the individual's needs.
- A team to support the individual may increase the chance that specific objectives will be achieved.
- Team members also would be in a position to identify and address problems as they arise.
- Without a person centred team in place an individual's unique needs could be easily unaddressed until a problem arose.

(Lumley & Scotti, 2001)

# Our Role


- Need to acknowledge it exists
  - **Value the clients sexuality**
- Approach subject with client
- Educate client
  - i.e. info pathology management e.g.. control of bowel and bladder, painful joints, reduced sexual response etc.
  - suggest alternate positions and encourage personal exploration



# Our Role

- Be aware of isolation and sensory deprivation. Provide opportunity for touch.
- Allow for masturbation instead of punishing
- Bring up sexuality as part of ADL
- Train client (and partner) on personal care and hygiene related to sexual activity
- \*\*\*Know when to refer to specialist





# Helping Individuals 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 client expression
- The needs of men and women are usually different
- Become aware of your own comfort/ discomfort zones
- Find strategies that work for you

# How do you incorporate sexuality into everyday practice?

## Strategies: Personal & Environmental

- ↑ self awareness
- develop knowledge base
- secure a common ground
- establish a conducive sex positive environment
- privacy
- develop an ethical code
  - Dignity
  - equality – nonjudgmental
  - variety of patterns of choice

# Questions Raised?





# Small Group Discussion

## Case Study: Rachel and Sam

- Rachel and Sam are two residents at an extended care center.
- Both Rachel and Sam have significant cognitive impairment
- On several occasions they were “caught” holding hands and in each others arms.
- One night Rachel was found in Sam’s room sleeping with Sam
- Both Rachel and Sam have adult children who are their guardians and who feel this relationship is inappropriate and should not continue.
- Please discuss this case and list
  - What are the key issues
  - What strategies would you use to address this issue

# Bibliography

- Ailey, S. H., Marks, B. A., Crisp, C., & Hahn, J.E. (2003). Promoting sexuality across the lifespan for individuals with intellectual and developmental disabilities. *Nursing Clinics of North America* 38: 229-252.
- American Academy of Pediatrics. (1996). Sexuality education of children and adolescents with developmental disabilities. *Pediatrics*, 97, 275-278
- Betz, C. L. (1994). Developmental Considerations of Adolescents with Developmental Disabilities *Issues in Comprehensive Pediatric Nursing* 17, (3): 111-120.
- Bonnie, R. J. (1992). Defendants with Mental Retardation. In Conley, R.W., Luckasson, R., & Bouthilet, G. N. (1992). *Criminal Justice System and Mental Retardation: Defendants and Victims*. Baltimore, MD: Paul H. Brookes.
- Brogan, M. (1996). The sexual needs of elderly people: Addressing the issue: Nursing Standard, 10 (24), 42-45.
- Doyle, D et al. (1999). Human sexuality in long-term care. Canadian Nursing, 95 (1)26-29.
- Janus et al. (1993). *The Janus Report on Sexual Behavior*. New York: Harper.

# Bibliography

- Kaplan, H (1990). Sex intimacy, and the aging process. Journal of American Academia of Psycholanalysis, 18(20), 185-205.
- Kaeser, F. (1992). Can people with severe mental retardation consent to mutual sex? Sexuality and Disability 10, (1): 33-42.
- Kopelainenene, J et al (1999). Sexual functioning among stroke patients and their spouses. Stroke, 30 (4), 715-719.
- Lindau S, et al (2007) A Study and of sexuality and health among older adults in the United States New England Journal of Medicine Aug 762 - 769
- Morley, JE. (2003). Geriatric Sexuality. Clin Geriatr Med, 19 (3):463-655.
- Niederbuhl, J. M., & Morris, C. D. (1993). Sexual knowledge and the capability of persons with dual diagnoses to consent to sexual contact.
- Pangman, V et al (2000) Sexuality and Chronically ill Older Adults: A social justice Issue. Sexuality and Disability Vol 18, No 1
- Pfizer First Global Sexual Health Survey 2002 – news wire release
- Shlesinger, B. (1996). The sexless years or sex rediscovered. Journal of Gerontological Social Work, 26 (1/2), 117-131.

# Society Views – Aging & Sexuality

1. Society fails to recognize the **importance** of sexuality to the well-being of the elderly.
2. Society helps to impose barriers which result in sexuality of older adults being devalued.
3. Sexuality is so closely identified with youthfulness, the stereotype of sexless older adults who are frail and inactive is a widely held belief.
4. Older adults who are experiencing chronic illness find themselves devalued, denied sexual expression and excluded from meaningful relationships
5. PDA seen as cute.



# Barriers To Sexual Expression: Organizational & institutional policies - prevent sexual expression

- Social isolation and overprotection may inhibit expression (Betz 1994)
- Opportunities to interact with others tend to be functional rather than opportunities for individuals to form meaningful personal relationships (Nunkoosing et al, 1997)
- Individuals in segregated settings may be denied the opportunity to form/maintain intimate relationships
- Family member, staff, and service providers often have attitudes and practices that deny the right to healthy sexual expression
- Additionally, families or agencies may intentionally have policies in place try to keep them from participating in intimate relationships. (Ailey et al 2003)

# Competency To Make Decisions Is Highly Contextual.

- Bonnie, 1992 argues that a person may be competent to make one decision but incapable of making another, even within the same proceedings.
- 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.

(Bonnie, 1992)

- 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 )

# Harm Reduction

## Benefits

- Prevention of STIs, pregnancy, and abuse are central to this approach
  - These are the major concerns regarding engagement in sexual activities among people with ID

## Limitations

- Not traditionally framed in the context of sexuality
- The eventual goal of harm reduction is abstinence (in the context of drug use)
  - This does not fit with the idea that sexuality is part of human development
- Focus on harm
  - Does not account for the full sexual experience – physical, emotional, social, cognitive
- Issue of capacity to consent still unresolved

# Social Model of Disability and Feminist Theory

- Emphasise the fact that conventional understandings of sexuality and disability fail to include the unique perspectives of individuals with mental disabilities.
- A feminist standpoint allows an analysis of previously occluded issues such as the impact of power relations on the nature of consent to sexual activity by persons with a mental disability.



# A Standpoint Epistemological Framework – Way of Knowing

- Highlights the fact that very unique and distinct issues arise for people with intellectual disabilities in relation to sexual activity
- These issues may not correspond to those which people without intellectual disabilities or even people with physical disabilities face.

# Inability To Give Consent

- **Health Sexual Expression** - If individuals show by their behavior that they wish to engage in certain forms of sexual contact, and if the treatment team judges that this contact can improve quality of individuals lives, 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)

*“ In focusing on an individualised notion of consent, rather than the conditions under which choices can be meaningful, the prevailing idea of sexual autonomy assumes the mind to be dominant and controlling, irrespective of ... circumstances.”*

(Doyle, 2010)

- the notion of consent to sexual activity by persons with intellectual disabilities, from both a sociological and legal standpoint, has been constructed from an ableist perspective, imposing a standard of normative cognition on consent and construes sexual activity from the perspective of the normative societal perspectives.

# Supporting Healthy Sexuality for Individuals with ID

- Framework of a person centred planning approach is proposed
  - access to information regarding sexuality
  - participation in romantic relationships including marriage
  - receipt of relevant support services as needed

(Lumley & Scotti, 2001)

# Case Studies

**Sarah:** a 31-year-old woman with intellectual impairment states a goal i.e. her dream of getting married. However, she is very shy and spends every evening alone in her apartment.

**Rick:** has severe intellectual impairment who attempts to engage in sexual intercourse with a nonconsenting roommate. Rick has no language,

(Lumley & Scotti, 2001)

# Case Studies - Approach

## **Sarah:**

A positive and possible goal to be achieved in one year may be to have a boyfriend.

Relevant Objectives:

- a) development of social skills necessary to initiate and maintaining a dating relationship
- b) increase participation in community activities and
- c) participation in sexual health education.

## **Rick:**

Due to limitation of his disability the team would work to identify goals and objectives based on their knowledge of him and his preferences.

A goal may be appropriate sexual gratification [i.e. does not infringe on the rights of others] which might be achieved by teaching Rick how to masturbate to climax.