

Sexual Health Education for Adolescents with Developmental Disabilities



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Sexual health education: Health promotion and abuse prevention

- ▶ Not done in isolation
- ▶ Sexual health education is only part of a broader picture and is not meant to put the onus on the child/adolescent to take full responsibility for their own safety
- ▶ Intersectionality – interaction between having many oppressive identities;
 - ▶ Results in facing multiple barriers
 - ▶ Challenge deficit-oriented practices and make transparent the ways in which wider social and institution structures create/perpetuate inequality.
- ▶ Societal barriers disable people – a systemic perspective is needed
- ▶ Also taking into consideration the social determinants of health
 - ▶ The social determinants of health influence the health of populations. They include income and social status; social support networks; education; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development; gender; and culture.

Background for the Research Project

Studies in general show that individuals with a disability experience 4-10 times greater risk for sexual abuse compared to the general public.

- ▣ According to a recent systematic review published in *The Lancet* persons with disabilities have a 50% higher risk of suffering violence and abuse (Hughes, et al., 2012)
- ▣ Children with disabilities have a threefold increased risk of having experienced violence compared to non-disabled children. (Jones, et al., 2012),
- ▣ More recently, during 2011-2015 in the United States, persons with intellectual disabilities experience the highest rate of victimization of all disability types (Harrell et al., 2017).
 - Among adults with developmental disabilities as many as 83% of females and 32% of males are victims of sexual abuse
 - This abuse is often not identified due to many barriers to disclosure
 - It is often unreported (estimated that only 20% of cases are reported)
 - When reported there is limited follow up and rare convictions

Sobsey & Varnhagen, National Clearinghouse on Family Violence,

Prevention Division, Health Canada: Ottawa. Various

(Frawley14; Northway, et al., 2009; Sol, 2013).



The vulnerability of young people with disabilities is intensified for a number of reasons:

- ▣ Isolation, limited cognitive abilities, language, speech or vocabulary barriers, dependence on others for personal care, risk of low self-esteem, depersonalization, powerlessness, lack of education on sexuality and abuse/harassment prevention, non-protective organizational structures and policies, physical defenselessness, compliance, and negative and inaccurate attitudes, myths, and stereotypes

(Bowman, Scotti & Morris, 2010; Health Canada, 2000; Martinello, 2014).



****Myths ****

- ▶ People with developmental disabilities are:
 - ▶ Asexual
 - ▶ Sexual perverts
 - ▶ Forever children
 - ▶ Do not have the ability to learn about sexuality or how to protect themselves
 - ▶ Will not have an intimate relationship with a peer
- ▶ As a result, often parents and teachers are less likely to provide appropriate sexual health education

Original Partners:





Creating Safe Environments Project

- Phase 1: Healthy Sexuality (2004-present)
- Phase 2: Healthy Peer Relationships (2012-present)
- Phase 3: Healthy Peer Relationships (2015-present) – **Peer to peer delivery**
- Phase 4: Healthy Dating Relationships(2016-present)- **Peer to peer**
- Film Production of the Safe Environments Project
- Nursing students and other interprofessional students have been involved in the delivery of the project since it's inception.
- Future: Train the trainer model in rural and remote areas



Research Project Content:

Overall Intents of the Creating Safe Environments Project

- Promotion of Healthy Sexuality
- Prevention of Sexual Abuse
- Students will have an understanding of:
 - Healthy peer relationships
 - Dating relationships
 - Consent in relationships
 - At-risk situations
 - Bullying
 - Boundaries
 - Assertive Communication
 - Identification and clarification of feelings



Specific Intents of the Safe Environments Research Project

Students to have an understanding of:

- ▣ Value of privacy and appropriate boundaries related to relationships
- ▣ Review correct names for body parts
- ▣ Inappropriate touching
- ▣ Inappropriate touching related to peer relationships
- ▣ Manipulation in relationships
- ▣ At-risk situations (secrets, bribes, tricks)
- ▣ Developing intimacy
- ▣ Diversity, inclusion and acceptance
- ▣ Talk (say NO), Walk (get away) and Squawk (tell someone you trust and keep telling until someone believes you and helps)

Educational sessions are provided to the teachers, teacher associates and the parents regarding sexual health of adolescents with developmental disabilities and possible disclosure.

Interactive Learning and Storyboards

Each delivery module consists of 4-5 (1 hour) sessions

- 2 sessions including games and interactive learning
- 2 sessions with storyboards (12 story boards to choose from with different scenarios)
- ▶ Storyboard illustrations created by local artist to reflect student population.



developed

Puppet Show

- ▶ Puppets created and designed by a local theatre company (Wide Open) to reflect the student population (Puppets with Character!).
- ▶ Scripts created by researcher, project manager and university students:
 - ▶ Inappropriate touching and disclosure (neighbour); inappropriate touching and disclosure (family member); healthy and unhealthy dating relationship (group home); dating violence
- ▶ Stories created by researcher, project manager and students.
- ▶ 3 different scripts – 4 scenarios





Community Development and Engagement

- Academia is encouraged to listen, learn, take direction from the community and negotiate a genuinely reciprocal relationship with mutual benefit for all (Kajner, 2015).
- Using this collaborative community development approach, I listened and learned from the community partners and heard their request to move forward with the intent of making a difference in the lives of adolescents with developmental disabilities and not doing research on them. It was important for the community partners to deliver a program that met the sexual health needs of this population and involved collaboration with all partners.
- Initially, the project identified literature related to healthy sexuality education for adolescents with developmental disabilities and explored possible delivery modes for knowledge transfer in this area.
- Secondly, available resources for adolescents with developmental disabilities were explored including human resources, institutional, and programming resources.
- Thirdly, integration of the community development model included ongoing consultation with community organizations.



Inter-professional Teams

► Meitheal

- An Irish word for a work team that conveys communal work in response to community needs.
- An interprofessional group consisting of professionals in education, health, counselling psychology, social work, and students from these disciplines offering mental health services for high school students with intellectual disabilities.
- Began 12 years ago at Holy Cross Catholic High School in Saskatoon, and is now working out of E.D. Feehan Catholic High School.
- Meitheal meets weekly to bring forward and collaborate on student cases to provide assessment, intervention, and ongoing evaluation.



Inter-professional Teams


► Student team

- Interprofessional student group nested within Meitheal, consisting of social work, educational psychology, and nursing students.
- Work independently within classrooms with high school students, teachers, and educational assistants as a part of the classroom team.
- Work collaboratively with Meitheal and each other to develop and deliver specialized interventions.
- Offers a unique opportunity towards the end of professional education program to build and maintain an interprofessional team within the context of mental health and education services.
- Each year the student interprofessional team develops and delivers a capstone project.



Environmental Scan

- ▶ Purpose: to find and examine current programs that teach sexual health to individuals with developmental disabilities in order to inform future curriculum development.
- ▶ The environmental scan included a literature search of six databases, and an in-depth analysis of current sexual health programs or curriculums throughout the world.
- ▶ The environmental scan returned nine programs that were available to evaluate in depth, and are included in the summary document. Evaluation summaries described each program, and discussed strengths and deficits.
- ▶ 17 articles were analyzed for themes, one of which was a systematic review.
- ▶ The literature search identified a need for detailed and cohesive curriculum that is responsive to learners' self-identified needs, and for improved evaluation of programming.



Interprofessional Student Group Experience

- ▶ Meitheal
 - ▶ Students were able to meaningfully participate in Meitheal and to contribute based on knowledge gleaned from the development of therapeutic relationships with individual students and participation in the classroom context.
- ▶ Student IP team
 - ▶ Met daily to develop and advance the group, to develop and work collaboratively on the capstone project (Environmental Scan), and to develop interventions tailored to perceived needs in each classroom (healthy relationships, self-esteem, personal safety).
 - ▶ Used a structured approach to group meetings to build rapport, address resistant behaviour within the group, to develop working strategies tailored to the group dynamic.
 - ▶ The experience was sometimes rocky, but always valuable learning in terms of the capabilities of interprofessional groups, barriers to effective group function, and the benefits to our clients of cohesive and collaborative work.



Meaningfulness

- ▶ Community organizations recognize there is a notable poverty of programs and services available to this population
- ▶ The project fills this gap by offering immediately accessible school-based mental health education.
- ▶ Prevention of abuse is important; however, it is also important to promote sexual health based on intimacy, safety and desire, rather than fear and overprotection (Murray, 2016). Adolescents with developmental disabilities need to protect themselves while appreciating and having the opportunity to develop an intimate and healthy relationship with someone they care for (Murray, 2016).
- ▶ People with developmental disabilities have the same sexual desires as those without a disability and they mature at basically the same rate (Barber, 2011; Swango-Wilson, 2008, 2011; Wings-Yanez, 2014). There remains, however, a stigma regarding their sexuality and people with developmental disabilities remain, "marginalized, oppressed, and left out of discussions of sexuality" (Winges-Yanez, 2014, p. 114).
- ▶ It may be argued that to deny the sexuality of a person on the grounds of their disability, is to deny them a basic human right (Barber, 2011).



Teaser clip and full video

- ▣ <https://www.youtube.com/watch?v=Ard9B1a-55w>

- ▣ The full length video is available on my faculty profile page,
College of Nursing, University of Saskatchewan

- ▣ College of Nursing News (2018, March). *Nursing in the Community: Healthy Relationships*. (L. Murray). University of Saskatchewan. Saskatoon, SK: Author. Retrieved from

- <http://nursinginthecommunitytest.usask.ca/healthy-relationships.php>

- (short teaser clip and full length video included)

Granting Agencies

- ▶ RBC Nurses for Kids, College of Nursing University of Saskatchewan
- ▶ President's SSHRC Grant, University of Saskatchewan
- ▶ Saskatoon Health Region - Community Grant
- ▶ Government of Saskatchewan - Community Initiatives Fund
- ▶ University of Saskatchewan - Community Engagement and Outreach
- ▶ Awl Shop
 - ▶ Bob Gibb





Partnerships and Future Directions:

Options for Development and Delivery?/

Original Partnership:

- College of Nursing
- Greater Saskatoon Catholic Schools
- Red Cross RespectED
- Saskatoon Sexual Assault and Information Center

Potential New Partners:

- ▶ Saskatoon Sexual Health
- ▶ Saskatchewan Prevention Institute
- ▶ Saskatchewan Alternatives Initiative
- ▶ Saskatoon Public Schools
- ▶ Creative Options Regina
- ▶ Saskatchewan Association for Community Living
- ▶ Community Living Service Division
- ▶ STEPS (Strategies to Engage and Promote Success)
- ▶ Saskatchewan Association of Rehabilitation Centres,