

## Comprehensive sexuality education, intellectual disability, and school personnel

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November 25 2008

## Presentation overview

- Rationale for topic
- Some definitions
- Literature review results
- What's next
- Discussion

## Comprehensive sexuality education and individuals with intellectual disabilities

- Historical perspective
- Personal experiences leading to choice of topic
- Current issues

## Definitions

- Sexuality education, *not* sex education
- Comprehensive sexuality education (CSE) versus other types of sexuality education
  - Sexuality Information and Education Council of U.S. (p.22)
    - [http://www.sieced.org/sexual\\_education.html](#)
  - Public Health Agency of Canada
    - [http://www.phac.gc.ca/2008/04/01/20080401-eng.htm](#)
- Personhood:
  - Construct
  - Its situation in my research topic
- Intellectual disability:
  - official, operational, individual definitions: problematic (A20)
    - [MOR legislation and policy - intellectual disability](#)
  - need for description to provide holistic view of the construct

## Research on comprehensive sexuality education and intellectual disability

- Findings on gaps in CSE provision include:
  - Decisions are value-laden and situational (Epstein & Johnson, 1998; Halstead & Reiss, 2003), rely on negotiation between right to information and protection from harm (Niederbuhl & Morris, 1993; Lyden, 2007; Stavis, 1991)
    - Question of power, values, beliefs, perceptions of sexuality of the power-holder
    - Often hinted at in the literature, but has yet to be fully explored and problematized (Howard-Barr, Rienzo, Pigg, & James, 2005; Peters, 2007)

## Examples:

- In discussion section of Howard-Barr et al. (2005), authors state that "they [special education teachers] do not view educable mentally disabled youth (sic) as sexual beings who need information on sexual behavior" (p. 103).
- In discussion section of study by Wolfe (1997), she states: "the results of the current study may highlight a conflict between personal values and the concepts of choice and dignity of risk for persons with disabilities. (...) Professionals must be aware of personal values and the effect they may have on the individual with whom they work. In the highly personal area of sexuality, it is important that professionals recognize that the values of the people with whom they work may be different from their own and, even if different, should be equally validated" (p. 88).
- In discussion section of study by Christian, Stinson, and Dotson (2001), authors state that: "understanding staff's attitudes and beliefs [regarding sexual expression] is an important step in understanding the climate in which services are provided to women with developmental disabilities" (p. 289).

### Examples:

- Discussion section of study by Swango-Wilson (2008) states:  
 "successful sexual programs for the individuals with ID [intellectual disabilities] must first address the attitudes and perceptions of the primary caregivers. The caregiver's role is essential if individuals with intellectual disability are to develop and function as members of society" (p. 5).
- Discussion section in Brown and Pirtle (2008) states:  
 "The focus of this study has been the beliefs concerning sex education for individuals with intellectual disabilities held by adults who are involved in the lives of these individuals. (. . .) How these beliefs affect the education provided to the individuals with intellectual disabilities has not been specifically addressed" (p. 71).

### Research on CSE and intellectual disability (continued)

- Lack of consensus on content; content reliant on many factors (Halstead & Reiss, 2003; Howard-Barr et al., 2005; Janney, 2001; Peters, 2007)
- Misperception regarding lack of support from administration, families, and communities (Constantine, Slater, & Carroll, 2007; Donovan, 1998; Howard-Barr et al., 2005; Johnson, 2005; Marsman & Harold, 1986; Peters, 2007; Stone & Ingham, 1998)
- Misperception regarding lack of proper training/lack of adapted curricula (Constantine et al., 2008; Howard-Barr et al., 2005; Johnson, 2005)

### Research on CSE and intellectual disability (continued)

- Many of these arguments do not stand up to scrutiny
- Most research on sexuality of individuals with intellectual disabilities has been quantitative (Howard-Barr et al., 2005; McCabe, 1999; McCabe & Cummins, 1996; McCabe & Schrack, 1992; Szollos & McCabe, 1995; Rinzo-Barr et al., 2005; Swango-Wilson, 2008), with bulk privileging perceptions of others such as 'experts', caregivers, teachers (e.g., Brown & Pirtle, 2008; Christian et al., 2001; Swango-Wilson, 2008; Wolfe, 1997).
- Sexuality typically negatively viewed, when associated with intellectual disability (Bernert, 2005; Brown & Pirtle, 2008; Howard-Barr et al., 2005; various McCabe studies, etc.)
- With consistent findings over time and across settings, this type of research no longer moves the question forward; does not help to explain why a gap persists between acknowledged need and actual provision

### Moving forward . . .

- Looking at problem in new ways:
  - Problematize negative associations
  - Seek explanations for views
  - Beyond recognition of diverging values, towards questioning of internal biases (e.g. lesser personhood)
  - Examine systemic discrimination

### How?

#### Alternative methodological approaches

- Since surveys and other quantitative methods limit types of obtainable data and since these methods cannot answer questions involving complex social phenomena: Other approaches may be more appropriate in trying to provide alternative interpretations

### Case Study methodology

- Can expose :
  - Role of ideology
  - Organizational dynamics
  - Social and political processes
  - Cultural values in situational practices and interpersonal interactions
- Potentially more inclusive due to multiple data sources
- Useful for measuring constructs

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