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Review article

## Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature

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### ABSTRACT

**Background:** There is a growing and evolving research evidence base regarding sexuality issues and adults with intellectual disabilities. Individuals can face challenges, including the right to express their sexuality and to access necessary education and supports.

**Aims:** This systematic review explores sexuality experiences, the views and opinions of adults with intellectual disabilities and highlights areas for future practice developments.

**Methods and procedures:** A comprehensive search of relevant databases from January 2006 to December 2016 was carried out. Included studies had to address specific criteria including: peer reviewed papers, the use of appropriate research methods, and focused exclusively on the individual views and opinions of people with an intellectual disability. The search of relevant databases yielded 230 hits. Following the application of explicit inclusion and exclusion criteria, 23 papers were deemed suitable for the review.

**Outcomes and results:** The data were analysed and key themes were identified that included: autonomy v's risk of harm, knowledge and sexuality, relationships and intimacy, self-determination and taking control, and encouragement and supports.

**Conclusions and implications:** Adults with intellectual disabilities need education and support to express their sexuality and to meet individual needs.

### What this paper adds?

Studies on the topic tend to present the views and opinions of families, carers and professionals. This review highlights issues from the available research that address the unique experiences of adults who have an intellectual disability. The discussion presents areas relevant to policy, practice education and future research priorities.

### 1. Introduction

The expression of sexuality, including how individuals form and maintain intimate relationships, is a fundamental part of being human (Krebs, 2007; Matich-Maroney, Boyle, & Crocker, 2005; World Health Organization, 2013). In health and social care settings, practitioners are paying more attention to issues related to sexuality in terms of the provision of the necessary psychosocial supports and education (Greenhill & Whitehead, 2010; Gascoyne, McCann, Quinn, & Hughes, 2016; McCann, 2010; Palumbo, 2016). Another important consideration is the emancipatory or human rights position whereby people have opportunities to explore and make

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decision around how they live their sexual lives (Officer & Shakespeare, 2013). For some, the only boundaries around sexual expression are that they do not include coercive sexual acts and that the right to express ourselves sexually is measured against an individual's rights to privacy and autonomy (Gomes, 2012). The World Health Organization expands their conceptualisation and understanding of sexual health concerns thus:

*...the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. Indeed, it has become clear that human sexuality includes many different forms of behaviour and expression, and that the recognition of the diversity of sexual behaviour and expression contributes to people's overall sense of well-being and health (World Health Organization, 2015, p4.)*

Furthermore, enlightened ways of supporting people in their expression of sexuality is evidenced in the move from a purely biomedical position to a more person-centred and inclusive approach that places rights, choices and voices at the hub of all health and social care developments (Thomas et al., 2017). The changing landscape should encapsulate fundamental human rights and social inclusion directives that encourages and supports the expression of sexuality (McCarthy, 2014; Wings-Yanez, 2014).

Concerns about the expression of sexuality in people with intellectual disabilities is not new and one that has attracted significant attention in the past and remains a contentious issue (Aunos & Feldman, 2002; Kempton & Kahn, 1999; Löfgren-Mårtenson, 2004; Wings-Yanez, 2014). Despite major policy shifts over the past 30 years regarding the care and support of people with intellectual disabilities, notably the closure of long-stay institutions, and the promise of more socially inclusive models of care and support, challenges still exist. The social model of disability emphasizes the human rights dimension of people with disabilities. However, account needs to be taken of the medical, psychological, social and political factors that impact upon individual's lives. Failure to effectively acknowledge and address health needs adequately is another example of discrimination and the further marginalization of people with intellectual disabilities (Shakespeare, 2012). With deinstitutionalization and a focus on the social model of disability it remains questionable the extent to which adults with intellectual disability have control over their lives and the opportunity to realise their potential, including the expression of their sexuality and all that this encompasses (Shakespeare, 2013).

## 2. Method

### 2.1. Research questions

The aim of this review is to synthesize current evidence regarding the experiences and perceptions of adults with intellectual disability regarding the expression of their sexuality and their support needs. Therefore, the questions of this review are:

1. What are the experiences and perceptions of adults with intellectual disabilities regarding their expression of their sexuality?
2. What are the sexuality experiences and needs of adults with intellectual disabilities in relation to education, supports and service utilization?

### 2.2. Search and selection strategy

A subject Librarian was enlisted to assist with the literature search strategy. The databases used in the search were CINAHL, MEDLINE, PsychINFO and Sociological

#### Abstract

The search terms used were: intellectual disab\* OR mental retard\* OR learning disab\* OR mental handicap OR developmental disab\* AND sexuality. The data were accessed from January 2006 to December 2016. An example of the search strategy used in one electronic database is shown in Table 1.

The searches resulted in 230 hits across all the databases. A hand search of reference list identified a further 2 papers. Duplicates and irrelevant articles were removed leaving a total of 141 papers to be considered. The 141 papers were screened by title and abstract against the inclusion criteria and a further 83 papers were excluded leaving 58 papers for full review. Following full review of the 58 papers, a further 35 were excluded on one or more of the following grounds: the study population did not exclusively look at sexuality issues and adults with intellectual disabilities; other reasons were that the sample included children and young people with

**Table 1**  
CINAHL search strategy and results example.

Search code	Query	Results
S1	intellectual disab*	11,956
S2	mental retard*	1592
S3	mental handicap	373
S4	developmental disab*	5738
S5	learning disab*	5740
S6	S1 OR S2 OR S3 OR S4 OR S5	20,896
S7	Sexuality	19,142
S8	S6 AND S7	329
	Limiters were English, peer reviewed, adults	71

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