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ORIGINAL ARTICLE

Sexual health of people with an intellectual disability: An ecosystem approach[☆]



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Summary The goal of this article is to propose a state of knowledge on the situation of people with an intellectual disability regarding their sexual health from factors that facilitate or obstruct it. Definitions of sexual health and disability suggest an ecosystem approach, which considers both personal and environmental factors that may have an impact on sexual life. A literature review confirms the role of intellectual restrictions and social configurations on the sexual health of people with an intellectual disability.

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Introduction

People with an intellectual disability have restrictions regarding cognitive functioning and adaptive behaviour that affect their conceptual and social skills, and their sexuality. Before the 1970s, people with an intellectual disability were seen as asexual beings who were not interested in sexuality. The fear of a suffered or committed aggression as well as an unwanted pregnancy gave grounds to prohibit sexuality. These people were considered unable to assume their sexual life. This perception has changed since the last four decades. For example, in 2008 the American Association on Intellectual and Developmental Disabilities adopted a policy

on sexuality recognizing the right of people with intellectual disabilities to live their sexuality (AAIDD, 2008). If their sexual needs were denied or solved by sterilization, they are now recognized and sexual health services are looking into it. People with an intellectual disability need support to prevent unwanted pregnancies, sexual abuse and sexually transmitted infections. Their intellectual restrictions make them vulnerable to these dangers. An increasing body of literature is studying these issues. Indeed, Gascon et al. (2010) examined the themes in the scientific literature from 1990 to 2007 that focused on adolescents with mental retardation and found that sexual life is in fifth position on a list of twenty-one.

Many people with an intellectual disability do not receive the necessary attention regarding sexual health (Servais, 2006). Consequently, they are subject to obstacles from their environment that oppose interventions to promote sexual health. Whether it is in terms of family, school or community, many obstacles can hinder sexual education initiatives. Thus, it becomes imperative to establish the state of knowledge on the situation of people with an intellectual disability and their sexual health in order to determine

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the factors that facilitate and obstruct it. This inventory could inspire service providers in the development of intervention projects with families, schools, social and health institutions, and community organizations. To carry out this work, definitions of sexual health, handicap and intellectual disability will be initially presented, to then adopt and implement a theoretical model that will be used to document the determinants of sexual health of people with an intellectual disability.

Conceptual framework

When social actors talk about sexual health, handicap and people with an intellectual disability, it is not clear that they refer to the same realities. It is therefore important to define these concepts in order to adopt a common language and evoke a fruitful dialogue. A conceptual work also helps to choose the theoretical model that will guide data collection. The content of these concepts must be determined by listing their characteristics and the related terms.

The World Health Organization (WHO) has proposed a definition of sexual health to guide decisions and actions of professionals. For the WHO, sexual health is a fundamental component of well-being and personal fulfillment: "Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled" (WHO, 2006, p. 5). The WHO proposes a holistic, multi-sectoral and interdisciplinary approach for the planning, the programming and the distribution of sexual health services. It considers individual and social factors that influence sexual health. It is important to remove barriers and develop strategies to promote sexual health.

Studying the sexual health of people with an intellectual disability requires a definition of this disability, which is difficult since it highlights a complex phenomenon involving several human dimensions. In France, legislation has proposed a definition of handicap in the [February 11 2005 law \(Loi no 2005-1002\)](#) for equal rights and opportunities, participation and citizenship of disabled persons. Article 2 states that "constitutes a handicap for people to be limited in their activities or restricted in their participation in social life due to the alteration of one or more physical, sensory, mental, cognitive or psychological functions, to a multiple disability or a disabling health disorder" (p. 2353, free translation). In Quebec, a disabled person is legally defined as "any person with a deficiency causing a significant and persistent disability, and who is liable to encounter barriers in performing everyday activities" (LRQ, 2011, chapter E-20.1, art. 1g, free translation). In 2006, one Quebecer out of ten lived with a disability (Camirand and Dugas, 2010). When considering all the disability categories, it should not be forgotten that people with disabilities are not a homogeneous and monolithic social group. These are people with distinct characteristics that contribute to their identity

development. As a result, they expect an appropriate response to their bodily and functional differences. Conceptual and intervention models concerning sexual health must consider the specific context of sexual life for each type of handicap. It therefore seems important to differentiate handicaps regarding sexual life (Mercier, 2005).

Several terms are used to describe intellectual disability, including retardation or mental disability. In its International Classification of Diseases (ICD-10), the World Health Organization (WHO, 2010) defines mental retardation as a "stop or incomplete development of mental functioning, characterized mainly by a change, during the period of development, of the faculties that determine the overall level of intelligence, namely cognitive, language, motor and social skills" (Chapter V. Mental retardation F70–F79, free translation). A standardized intelligence test is generally used to determine the degree of mental retardation: mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34) and profound (IQ below 20). Mental retardation will be diagnosed from an overall assessment of the person's abilities to function in a social environment. In Quebec, the authoritative definition of intellectual disability comes from the American Association on Intellectual and Developmental Disabilities (AAIDD, 2011): "Intellectual disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18" (p. 6). Approximately 3% of the Quebec population have an intellectual disability. Of these, 90% have a mild mental retardation (MSSS, 2001). People with an intellectual disability have significant restrictions regarding intellectual functioning (e.g. lack of reasoning, planning and problem solving) and adaptive behaviour (e.g. difficulties to communicate, meet standards and take care of themselves). Although they have difficulty learning, this does not prevent them from acquiring knowledge and skills.

Theoretical model

The concept of handicap is broad, which makes it particularly suitable for various situations. Conceptual changes introduced by the International Classification of Functioning, Disability and Health (ICF), developed by the WHO in 2001, bring new perspectives: including health problems (according to the Classification of Diseases – ICD-10), it takes into account the related areas of health. Therefore, people with a disability are not evaluated based on the degree of their impairment, but their adaptation to different functioning areas contributing to their general well-being, including their physical, psychological and social aspects within human life. This new approach considers people with disabilities as social actors, highlighting their activities and involvement. It is a privileged instrument to develop more respectful government policies on Human Rights for people with disabilities, based on their expertise as citizens. The ICF also allows working precisely on the impact of environmental factors that are present either as obstacles or as facilitators.

The ICF model integrates an ecological and systemic perspective focusing on people with disabilities and their

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