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Review article

Topics, methods and challenges in health promotion for people with intellectual disabilities: A structured review of literature



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ABSTRACT

People with intellectual disabilities (ID) experience substantial health inequities compared, with the general population. Many secondary conditions and lifestyle related health problems could be, prevented with adequate health promotion. The aim of this structured review is to provide insight into, the main characteristics of published health promotion intervention studies for people with ID and, in, doing so, to identify best practice and knowledge gaps. Relevant studies were identified through a, structured literature search of multiple electronic databases (PubMed, CINHAS, Scopus, PsychINFO), the search strategy covered health promotion and intellectual disabilities for available papers, published between February 2002 and 2012. In total, 25 studies were included and analyzed. Overall, studies were diverse and explored a variety of health issues. Papers included a variety of participants (in relation to level of disability) and intervention approaches. With regard to quality, many studies, failed to report how they recruited their participants, and there were substantial challenges identified, by authors in relation to recruitment, implementation of interventions, and the selection of outcome, measures used as well as the usability of measures themselves. Our findings suggest that this field, experiences methodological weaknesses and inconsistencies that make it difficult to compare and, contrast results. Theoretically driven studies that take into account the views and expectations of, participants themselves are needed, as is research that investigates the reliability and validity of, outcome measures for the ID population. Collaboration with mainstream health promotion research is, critical.

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1. Introduction

People with intellectual disabilities (ID) experience poorer health and higher risk of health problems compared with the general population. Although ID in itself is not a disease, health problems can originate from disabilities and the health of people with ID is adversely influenced by a cascade of disparities including inequitable access to health services (Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz et al., 2005; Van Schrojenstein Lantman-de Valk & Walsh, 2008). Many secondary conditions, co morbid conditions and lifestyle-related health problems experienced by people with ID can be prevented (Van Schrojenstein Lantman-de Valk & Walsh, 2008). Effective and accessible health promotion could contribute significantly to improve quality of life of people with ID and reduce costs related to preventable health problems (Van Schrojenstein Lantman-de Valk & Walsh, 2008). However, currently international focus on health promotion for people with ID is inadequate and needs more attention from researchers and decision makers (Krahn et al., 2006), as is reflected in several policy documents from the United States and Europe that make improving the health of people with ID a specific aim (Pomona project, 2008; US government, 2010).

The World Health Organization defines health promotion as: the process of enabling people to increase control over and improve their health (WHO, 1986). The term health promotion is often used interchangeably with other terms such as 'health education' and 'disease prevention'. Although all of these strategies aim to improve health, some distinctions can be made. Disease prevention aims to prevent the occurrence of disease by reducing risk factors for and the consequences of disease through early detection and treatment (WHO, 1998). Health education is concerned with the communication of information about health and fostering skills, motivation and confidence necessary for people to take action to improve their health (WHO, 1998). Finally, health promotion not only embraces actions directed at strengthening the skills and capabilities of individuals, but those directed at changing social, environmental and economic conditions to alleviate their impact on public and individual health as well (WHO, 1998). Since people with ID often depend heavily on their social and environmental context to support them to make choices and access facilities (Messent, Cooke, & Long, 2000; Segal, 1993) health promotion strategies offer important advances over prevention or health education.

People with ID experience important health determinants and disease-related risk factors differently from the general population due to physical, cognitive and behavioral impairments; and inequalities across mobility, income, living conditions, housing schemes and social networks. Thus, they have different health promotion needs, particularly in relation to the accessibility of health promoting activities (Robertson et al., 2000). The perceptions and knowledge of supporters with regard to healthy lifestyles, possibilities and needs of people with ID for health promotion are also important (Temple & Walkley, 2007; Young, Chesson, & Wilson, 2007). Available health promotion activities for the general population often assume a certain level of independence, can be difficult to understand, expensive, inaccessible or invisible to people with ID or their supporters – all barriers to participation (Messent, Cooke, & Long, 1999; Messent et al., 2000). Further, public health research that aims to evaluate health promotion activities may passively or actively exclude people with ID due to the challenges of recruiting and working with this group (Lennox et al., 2005). In the context of health disparities encountered by people with ID and their special needs for health promotion as outlined above, insight in existing health promotion projects for people with ID would be helpful in identifying research priorities, best practice and knowledge gaps.

The aim of this structured review is to identify papers that present an evaluation of a health promotion activity targeting people with ID and to describe the (1) health promotion activity implemented; (2) research design employed, including the recruitment strategy used; and (3) outcome measures used. A secondary objective is to describe the challenges associated with implementing and evaluating the interventions.

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