



Review article

Health assessment instruments for people with intellectual disabilities—A systematic review



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ABSTRACT

Background: People with intellectual disabilities (ID) experience health disparities and are less likely to undergo recommended age- and gender-specific screening and health promotion. New diagnoses are frequently missed. Assessments with the aid of health assessment instruments are a way to address these problems.

Aim: The aim of this review is to find the available health assessment instruments for people with ID used in primary care and evaluate their quality.

Methods: We conducted an electronic literature search of papers published between January 2000 and May 2016. After a two-phase selection process (κ : 0.81 and 0.77) we collected data from the 29 included peer-reviewed articles on the following four domains; *development*, *clinimetric properties* (i.e. validity, reliability, feasibility, acceptability), *content* (i.e. ID-related health problems, prevention and health promotion topics) and *effectiveness* of the instruments.

Results/Conclusions: We distinguished 20 different health assessment instruments. Limited information was found on the *development* of the instruments as well as on their *clinimetric properties*. The *content* of the instruments was rather diverse. The included papers agreed that health assessment instruments are effective. However, only three instruments evaluated *effectiveness* in a randomised controlled trial. Patients with ID, carers with ID, and general practitioners (GPs) generally appreciated the health assessment instruments.

Implication: Two instruments, “Stay well and healthy –Health risk appraisal (SWH-HRA)” and the “Comprehensive Health Assessment Programme (CHAP)”, appeared to have the highest quality. These instruments can be used to construct a health assessment instrument for people with ID that meets scientific standards.

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What this paper adds

People with ID experience health disparities. The prevalences of certain diseases (e.g. epilepsy, osteoporosis, visual impairment) in the population of people with ID differ from those in the general population. Health assessment instruments can guide health care professionals to reveal the health needs of people with ID. In this study, the quality of the health assessment instruments was assessed on four domains; *development*, *clinimetric properties*, *content* and *effectiveness*. We found 20 health assessment instruments. None of the instruments scored positive on all domains. People with ID, carers, and GPs generally appreciate the health assessments.

1. Introduction

People with intellectual disabilities (ID) are a vulnerable group in society. They have twice as many health problems as the general population, and their health needs are often unrecognized and unmet (Straetmans, van Schrojenstein Lantman-de Valk, Schellevis, & Dinant, 2007). Furthermore, patients with ID receive four times more prescriptions as the general population, often for psychotropic medication (Straetmans et al., 2007). Reducing psychotropic medication leads to better behavioural functioning, and reduces the BMI, waist circumference and systolic blood pressure (de Kuijper, Evenhuis, Minderaa, & Hoekstra, 2014). People with ID are at risk of significant patient and/or doctors delay in recognizing diseases (Heslop et al., 2013). Adults with ID are less likely to undergo recommended age- and gender-specific screening. This has been shown, for example, for colorectal, breast and cervical cancer (Ouellette-Kuntz, Cobigo, Balogh, Wilton, & Lunskey, 2015; Sullivan et al., 2003). People with ID also face more risk factors, such as overweight or obesity (de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012; Holder, 2015).

Health assessments can bridge the gap described above (Cooper et al., 2006; Felce et al., 2008; Hoghton, Martin, & Chauhan, 2012; Martin, 2003; Lennox et al., 2007; Slowie & Martin, 2014). The prevalences of certain diseases (e.g. gastro-esophageal reflux disease, epilepsy, osteoporosis, visual impairment) in the population of people with ID differ from those in the general population (Schipper, 2014). Health assessments for the general population often focus on one specific disease (e.g. cardiovascular risk) and are not comprehensive (Krogstøll, Jørgensen, Grønhøj Larsen, & Gøtzsche, 2012; Thomsen et al., 2005). People with ID often do not come forward with their health complaints and GPs are not always aware of the highly prevalent diseases in this group. Health assessment instruments specific to people with ID can help the GPs to focus on health problems that have a relatively high prevalence among people with ID (e.g. epilepsy, reflux disease). Health assessment instruments for people with ID often consist of three elements: new disease detection, age- and gender-specific preventive screening, and health promotion. One study on a Comprehensive Health Assessment Programme (“CHAP”) for people with ID, showed increased detection of vision impairment, hearing loss, and new diseases in adults with ID (Lennox et al., 2010). A systematic review and its recent update on the impact of health assessments for people with ID showed that health assessments consistently led to detection of unmet health needs and targeted actions to address those health needs (Robertson, Hatton, Emerson, & Baines, 2014; Robertson, Roberts, Emerson, Turner, & Greig, 2011). Furthermore, a longitudinal cohort study that used data from the Health Improvement Network primary care database showed that more blood tests, more general health measurements and more medication reviews were done (Buszewicz et al., 2014).

In most countries, GPs and nurses are involved in delivering health care to people with ID. However, these primary care professionals often lack the knowledge about specific diseases in patients with ID, and the time to deliver the necessary care

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