



Review article

Active involvement of people with intellectual disabilities in health research – A structured literature review



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ABSTRACT

Actively involving people with intellectual disabilities (ID) in health research, also known as inclusive health research, is increasingly popular. Currently, insight into experiences of this type of research is scarce. To gain insight into this topic, a structured literature review was conducted focussing on (1) existing theories, (2) inclusive methods, (3) added value and (4) barriers and facilitators. Literature published between January 2000 and January 2014 was included covering keywords related to ID and inclusive health research. Searches were performed in Pubmed, CINAHL, PsycINFO, EMBASE and MEDLINE databases, resulting in 26 included papers. Papers were quality assessed and analysed using qualitative data analysis software. Four theories were often simultaneously addressed: participatory research, emancipatory research, inclusive research and Arnstein's ladder. Barriers and facilitators could be divided into preparing, undertaking and finalising phases of research. Authors indicated that their motivation to conduct inclusive health research was based on demands by policy and funding bodies or was based on ethical considerations (i.e., ethical notions and giving people with ID a voice). Upon completion, authors perceived increased quality and validity of their research and several benefits for stakeholders (i.e., people with ID, researchers and healthcare professionals). Overall, there was consistency in their perception of the most important aspects of inclusive health research. Based on the analysis of included papers, four recommendations of inclusive health research with people with ID were found. Inclusive health research should be: (1) tailoring to the specific study; (2) anticipating all stakeholders; (3) considering its added value; and (4) providing insight into its process.

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Contents

1. Introduction	272
2. Methods	273
2.1. Search strategy	273
2.2. Working definition	273

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2.3.	Data analysis	273
2.4.	Quality criteria	274
3.	Results	275
3.1.	General characteristics	275
3.1.1.	Moment of inclusion	275
3.2.	Theories	275
3.2.1.	Participatory research	275
3.2.2.	Emancipatory research	275
3.2.3.	Inclusive research	275
3.2.4.	Arnstein's ladder of citizen participation	278
3.3.	Inclusive methods	278
3.3.1.	Interviews	278
3.3.2.	Focus groups	278
3.3.3.	Research partners	278
3.4.	Added value	279
3.5.	Barriers and facilitators	279
3.5.1.	Preparing phase	279
3.5.2.	Undertaking phase	280
3.5.3.	Concluding phase	280
4.	Discussion and conclusion	280
4.1.	Theory: lack of clarity	281
4.2.	Inclusive methods: best practices	281
4.3.	Added value: expected vs. experienced	281
4.4.	Barriers and facilitators: myth of homogeneity	281
4.5.	Strengths and limitations	281
4.6.	Conclusions and recommendations	282
	Acknowledgements	282
	References	282

1. Introduction

The idea that research “should not only be conducted ‘on’ patients but ‘with’ patients actively involved in decision-making” (p. 3) is increasingly popular (Elberse, 2012). Researchers realise that, in order to align research outcomes with patients’ needs, they should be actively involved. Three main drivers of active involvement were found in related literature: (1) patients have the democratic right to be involved in everything that affects their lives, including scientific research (Elberse, 2012; Nierse & Abma, 2011; United Nations, 2015), (2) inclusive research relies on experiential knowledge of patients, which is considered to be an important “source of knowledge” (Caron-Flinterman, Broerse, & Bunders, 2005), and (3) inclusive research is expected to lead to a better match between research outcomes and practice (Elberse, 2012). In addition to these drivers, national policies and funding bodies often demand inclusion of patients in research (Boyden, Esscopri, Ogi, Brennan, & Kalsy-Lillico, 2009; Tuffrey-Wijne & Butler, 2010; United Nations, 2004; Walmsley, 2004).

Active involvement of patients in research is prevalent in research concerning physical disabilities (e.g., rheumatism, lung diseases, cancer and burn victims). Involvement of people with intellectual disabilities (ID) as active participants in research is increasing (Walmsley & Johnson, 2003). As a result, more and more experiences are gathered regarding the active involvement of people with ID in research, however, a shared knowledge base is lacking. In addition, active involvement in research remains challenging, as people with ID are often assumed to lack the capacity to understand and discuss research related topics (Tuffrey-Wijne, Bernal, Butler, Hollins, & Curfs, 2007). They are often protected by well-intentioned family and carers (Tuffrey-Wijne, Bernal, Jones, Butler, & Hollins, 2006). In addition, Marshall (2012) believes that researchers might hesitate to include people with ID due to ethical concerns, since they are considered to be vulnerable and, therefore, should be protected from harm (Marshall, 2012).

There is an increasing demand for the active involvement of people with ID in research; however, sharing experiences of this research type is difficult. Firstly, views differ on which research methods lead to active involvement. According to Abma, Nierse, and Widdershoven (2009), there is a difference between methods that view patients as “active participants” versus as a “source of information” (p. 402). Secondly, literature on active involvement of people with ID in research uses a spectrum of terms. These terms are often used interchangeably, even though their meanings appear to be slightly different (Burke et al., 2003; Elberse, 2012; Tuffrey-Wijne & Butler, 2010). The multiple terms used in the literature suggest there is no consensus yet. Examples include: “inclusive research” (Walmsley & Johnson, 2003), “participatory research” (Morgan, 2013), “emancipatory research” (Walmsley, 2001), “participatory action research” (Garcia Iriarte, 2008), “patient participation” (Elberse, 2012) and “patient and public involvement” (INVOLVE, 2015). It is therefore important to clarify that this review adopts the term “inclusive research” as this is seen as the overarching term of people with ID’s involvement in research. Inclusive research is defined as: “research which includes or involves people with learning disabilities as more than just subjects of research” (Walmsley & Johnson, 2003, p. 61). This review paper specifically focuses on inclusive *health* research,

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