



Review article

Carer-led health interventions to monitor, promote and improve the health of adults with intellectual disabilities in the community: A systematic review<sup>☆</sup>



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ARTICLE INFO

Article history:

Received 18 November 2013  
 Received in revised form 6 January 2014  
 Accepted 6 January 2014  
 Available online 2 February 2014

Keywords:

Carer-led intervention  
 Intellectual disability  
 Learning disability  
 Health promotion  
 Health checks  
 Carers  
 Health intervention  
 Health services

ABSTRACT

Using carers to help assess, monitor, or promote health in people with intellectual disabilities (ID) may be one way of improving health outcomes in a population that experiences significant health inequalities. This paper provides a review of carer-led health interventions in various populations and healthcare settings, in order to investigate potential roles for carers in ID health care. We used rapid review methodology, using the Scopus database, citation tracking and input from ID healthcare professionals to identify relevant research. 24 studies were included in the final review. For people with ID, the only existing interventions found were carer-completed health diaries which, while being well received, failed to improve health outcomes. Studies in non-ID populations show that carers can successfully deliver screening procedures, health promotion interventions and interventions to improve coping skills, pain management and cognitive functioning. While such examples provide a useful starting point for the development of future carer-led health interventions for people with ID, the paucity of research in this area means that the most appropriate means of engaging carers in a way that will reliably impact on health outcomes in this population remains, as yet, unknown.

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## 1. Introduction

### 1.1. Health inequalities in ID

Physical and mental health inequalities have been well documented for people with intellectual disabilities (ID) (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Emerson, 2011; Emerson, Baines, Allerton, & Welch, 2010; Janicki et al., 2002; Kerr et al., 2003; Servais, 2006; Straetmans, van Schroyen, Lantman-de Valk, Schellevis, & Dinant, 2007; Underwood et al., 2012). Although there have been substantial increases in life expectancy for people born with ID over the past 60 years (Bittles et al., 2002; Hollins, Attard, von Fraunhofer, McGuigan, & Sedgwick, 1998; Puri, Lekh, Langa, Zaman, & Singh, 1995; Yang, Rasmussen, & Friedman, 2002), their median age at death remains far below that of those without ID, with the disparity increasing with the severity of the ID (Bittles et al., 2002; Glover & Ayub, 2010; Thomas & Barnes, 2010).

The most recent data published on life expectancy comes from a confidential inquiry into the premature deaths of people with ID in the UK (Heslop et al., 2013). The review covered all deaths ( $N = 247$ ) between 1st June 2010 and 31st May 2012, of people with ID aged 4 years or older, who were registered with a GP in one of 5 areas in South West England. The median age at death for men with ID was 13 years below that of men in the general population – for women the difference increased to 20 years. Just under half (48%) of these deaths were deemed to have been ‘avoidable’, meaning they could have been avoided through good-quality healthcare (‘amenable’ deaths) or through public health interventions (‘preventable’ deaths) (Heslop et al., 2013).

### 1.2. Health checks

In light of the increasing awareness of health inequalities, and of the barriers to accessing good quality healthcare often experienced by people with ID (Alborz, McNally, & Glendinning, 2005; Backer, Chapman, & Mitchell, 2009; Krahn, Hammond, & Turner, 2006; Redley, Banks, Foody, & Holland, 2012), several countries have in recent years introduced primary care health checks for this population (Barr, Gilgunn, Kane, & Moore, 1999; Lennox et al., 2007; NHS, 2008; Webb & Rogers, 1999). Research has found that health check programmes for adults with ID identify unmet health needs (Baxter et al., 2006; Lennox et al., 2007), however their longer-term impact on health outcomes remains to be established.

### 1.3. Carer-led interventions

For those adults who have difficulty recognising and gaining treatment for their health needs, carers, whether paid or voluntary staff, family, or spouse carers, may be in a position to monitor illness symptoms, promote healthy lifestyles, or advocate between the adults they care for and their healthcare providers (Langan, Whitfield, & Russell, 1994). By holding such a key role in the daily lives of people with ID, carers could potentially provide a useful resource in terms of more formally assessing and monitoring health needs and promoting positive health outcomes in the person they care for. Certain existing ID health checks include carers in the health check process, to provide support, advocacy and information about the patients’ past and present health status (Lennox et al., 2007; Turk et al., 2010), however the impact of such interventions on health outcomes is unclear, and adherence tends to be poor.

The primary aim of this study was to conduct a rapid, systematic literature review of existing health interventions led by carers. We conducted a broad search, across age-groups which was not limited to the ID population, in order to find examples of, and outcomes from, carer-led health interventions in a variety of settings. The results of this review may inform future

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