Review article

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

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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 Schrojenstein 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

research to develop and evaluate carer-led interventions to improve the primary care and health outcomes of individuals with ID.

2. Method

2.1. Search strategy

We used rapid review methodology (Ganann, Ciliska, & Thomas, 2010; Watt et al., 2008). Literature was identified via four main sources: the Scopus database, citation tracking, hand-searching reference lists and expert input. Several people working and publishing in the field of health care provision and ID were asked to identify any evidence-based carer-led interventions that they were aware of. Scopus was chosen as the search database, as it is currently the largest abstract and citation database of peer-reviewed literature, and has 100% Medline coverage ("SciVerse Scopus Facts & Figures," 2010). Initial searches were conducted in February 2013. Citation tracking included following 'cited by' links in Scopus searches, and setting up the searches themselves such that any articles meeting the search criteria that were published after our initial search, would automatically be added to the list. 31 May 2013 was deemed the end date for adding new literature.

We included the following search terms: TITLE-ABS-KEY ("carer-led" OR "caregiver-led" OR "carer-assisted" OR "caregiver-assisted" OR "carer-directed" OR "caregiver-directed" OR "parent-led" OR "parent-assisted" OR "parent-directed" OR "spouse-led" OR "spouse-assisted" OR "spouse-directed") AND health AND ("intervention" OR "check" OR "monitor*" OR "program" OR "review").

2.2. Criteria for selection

Inclusion criteria were: original research; published in English-language, peer-reviewed, academic journals; concerning carer-led interventions for improving, monitoring, screening or promoting physical or mental health, in healthy or clinical populations. Adult and child participants older than 2 years were included. 'Carers' included paid or voluntary care staff, family or spouses/partners. Review papers were excluded from the final list, but they were used for hand-searching original research articles. Additional exclusion criteria were single case studies, method papers not reporting outcomes from the intervention, infant participants (less than two years old), interventions not led by a carer, carer-led interventions not targeting physical or mental health, grey literature and papers published in languages other than English.

The titles and abstracts of all articles were initially assessed for inclusion by the lead researcher (RH). Potentially qualifying papers were read in full to extract details about the study design and method, participants, carer group, intervention, controls used and main findings. Final decisions on inclusion of the studies were agreed by the review team (RH, AS and MB) and all authors contributed to interpretation and integration of the findings. The reviewers were not blind to the authors, institutions or journal of publication when assessing the eligibility of the papers.

2.3. Quality assessment

The level of evidence provided by each study was agreed by two researchers (RH and AS), using the levels of evidence hierarchy published by the Centre for Evidence-Based Medicine (Howick et al., 2011). The scale runs from 1A to 5, where 1A is the highest level of evidence possible (i.e. a systematic review of randomised controlled trials (RCTs)) and 5 the lowest (expert opinion without explicit critical appraisal). These ratings were used to help describe the evidence found, with greater attention given to those studies that provided a higher level of evidence. The interventions themselves, and the methodology and outcomes used to assess them, varied widely. It was not possible to quantitatively assess the efficacy of carer-led interventions, thus results will be presented in the form of a narrative review, with studies combined by common themes.

3. Results

3.1. Overview of the included studies

Fig. 1 shows the results of the search process and reasons for excluding studies.

24 papers were included in the final review. An overview of these studies, including the carer group, patient group, setting, study method, main findings and evidence rating is provided in Table A1.

3.1.1. Summary of results
The interventions included in the final list were divided into the following themes (number of papers; total number of participants included):

- carer-led pre-health check questionnaires and patient-held records (3; $N = 503$),
- carer-led interventions for health promotion (12; $N = 3498$),
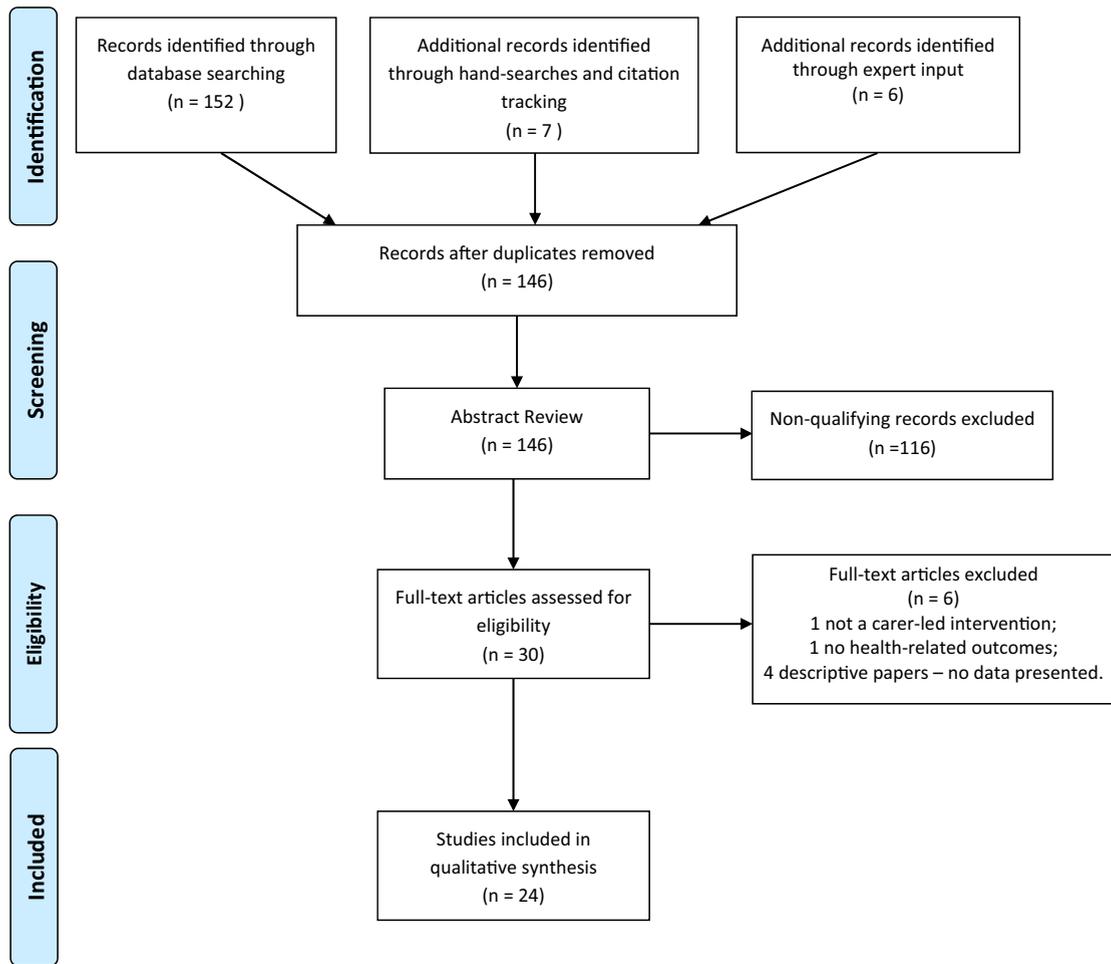- carer-led symptom monitoring and management (4; $N = 445$),

Fig. 1. Flow chart of the reviewing process.

- carer-led interventions for mental health (4; $N = 267$),
- screening delivered by carers (1; $N = 108$).

3.2. Carer-led pre-health check questionnaires and patient-held records

The Comprehensive Health Assessment Programme (CHAP) and Advocacy Skills Kit Diary (ASK Diary) were developed in Queensland, Australia, by Lennox and Colleagues (Lennox, Rey-Conde, & Faint, 2008; Lennox et al., 2010). The CHAP includes an extensive pre-check questionnaire that is completed by a carer, followed by a GP-led health check. The ASK diary combines a physical health record and information for GPs working with people with ID, with advocacy skills training provided for the person with ID if able to self-advocate, or those advocating on behalf of someone in their care. The intention is to improve communication between health professionals, people with ID and their carers and the diary has been designed for continual use in all healthcare environments.

An initial feasibility study with 30 adolescents with ID found that the CHAP was effective at identifying unmet health needs and increasing health-related activity. However the ASK diary, although popular with the participants, their parents and their teachers, did not lead to improved communication levels: despite initially stating their intention to 'speak up' in the health check, not one of the adolescents in the study reported asking a question, or requesting further information, during medical visits (Lennox et al., 2008).

A later four-arm cluster RCT compared the effects of the CHAP and ASK Diary with care as usual in adults with ID (Lennox et al., 2010). This trial provides strong evidence for the efficacy of the CHAP in identifying previously unmet health needs and increasing health-related activity. However, neither this RCT nor the earlier pilot study considered the impact of the initial carer-led questionnaire in isolation from the GP-led section of the CHAP. As such, conclusions about the effect of including carers in the health check process are difficult to draw. The RCT found that the ASK diary had no quantifiable impact on

measured health outcomes, which included vaccination rates and clinical activity such as vision checks or weight monitoring. However, exit interviews with 94 carers revealed that 19% of them had never used the diary: any effects could therefore have been under-estimated.

Poor adherence was also a key concern for Turk and colleagues, who developed and trialled a personal health profile (PHP) for adults with ID in London, UK (Turk et al., 2010). The PHP aimed to improve health knowledge in the individual with ID, their carers and health professionals, and could be updated by anyone involved in the individual's care. Despite more than 90% of adults with ID and their carers expressing satisfaction in having the PHP and 87% saying it helped them know more about their health or the health of the person they cared for, in exit interviews only 66% of adults with ID and 55% of carers reported actually using the profile. Furthermore, when adults with ID or their carers were asked whether they had a particular condition, there was no difference in valid responses between the PHP group and controls during the follow-up assessments. This indicated that the PHP did not lead to significant increases in personal or general health knowledge, in either adults with ID or their carers. The profile did not lead to significant increases in attendance at GP or other healthcare services.

Taken together, these three studies provide little support for the use of carer-completed health records as a means of improving communication with health professionals or short-term health outcomes for people with ID.

3.3. Carer-led interventions for health promotion

3.3.1. Parent-led interventions for managing childhood overweight and obesity

In a pilot RCT involving 50 families, Moens and Braet (2012) found that a combination of healthy lifestyle, behaviour change and parenting training for parents of overweight children led to significant reductions in their child's BMI. The BMI in a wait-list control group (WLC) did not change significantly. Comparisons with a reference group, composed of children whose parents had chosen not to take part in the main study, found that members of the reference group were no different to the intervention group in terms of the child's gender, age or BMI at baseline, but showed significant increases in BMI 12 months later. While showing that developing a variety of skills in parents can lead to positive health outcomes for their children, this research did not consider how the different components of the intervention might have impacted on BMI reduction.

Two earlier RCTs were more comprehensive: Golley, Magarey, Baur, Steinbeck, and Daniels (2007) randomised the parents of 111 overweight pre-pubertal children to parenting skills plus lifestyle education (PS + LE), parenting skills (PS) alone, or WLC. Participants in the PS + LE and PS groups both showed significant reductions in BMI Z-score and waist circumference over the 12-month study period, whereas those in the WLC showed a smaller reduction in BMI, and no significant change in waist circumference. Magarey et al. (2011) composed their groups in the converse fashion: parenting skills training was combined with healthy lifestyle training (N = 85) and compared to lifestyle training alone (N = 84). Participants achieved an average 10% weight loss in both groups, indicating no additional benefit from combining the healthy lifestyle training with parenting skills.

A further RCT from Golley, Magarey, and Daniels (2011) on overweight pre-pubertal children, used the same three conditions (PS, PS + LE and 12-month WLC) with the child's food intake and activity levels reported by parent completed questionnaires as the outcome measures. Mean daily consumption of 'extra' food (defined as energy-dense, nutrient-poor foods) significantly reduced in both intervention groups, with reductions being maintained for up to 6 months. Food intake was unchanged in the WLC group and there were no significant differences between the groups in terms of activity levels, at any stage of the study.

Resnick et al. (2009) randomly assigned 46 parents to a health education intervention, delivered through the post, or via contact with a health worker. Intervention materials included a cookbook, physical activity book, pedometer and information about making healthy eating and activity choices. Although parent-report measures showed no significant increase in parental knowledge after the intervention, their children's BMI percentile reduced by an average of 5 points over the 41-week period. No significant difference in BMI percentiles was seen between the groups, indicating that the materials had a similar effect whether read alone by the parents or delivered by a health worker. A non-randomised contemporaneous control group was found to have no change in BMI during the same period. Small and colleagues conducted a pilot study of an educational intervention for 45 mothers of 4–6 year old children (Small et al., 2012) and found that their educational intervention, consisting of nutritional information and practical serving tips, also failed to increase parental nutrition knowledge, but did lead to reductions in the average amount of calories served to, and consumed by, the children.

These combined results show that targeting parents can lead to improvements in health promotion and healthier lifestyles in their children. Parenting or healthy lifestyle skills training may lead to reductions in children's food consumption and BMI and can be achieved by providing parents with appropriate educational materials, even when these materials do not appear to be improving the parents' knowledge. However, in the current studies such improvements have been small and the mechanisms behind such health improvements, in the absence of a clear impact on parental knowledge, remain unexplored.

3.3.2. Parent-led interventions to improve feeding problems

A pilot study by Dovey and Martin (2012) targeted problem feeding in 17 children whose problems resulted from sensory defensiveness. Following a 6-month, parent-led, contingent reward desensitisation intervention, which included children receiving reward tokens after trying problem foods, the children's population-corrected height and weight had increased significantly, although BMI changes did not reach significance.

A previous RCT of 156 parents of 2–6 year old healthy children by Wardle et al. (2003) had found that children whose parents were taught to lead a 14-day, graduated food exposure programme showed greater increases in liking, ranking and consumption of target vegetables than children whose parents only received nutritional advice or WLC. In the exposure group, these increases were all significant. The control group showed small, but significant increases in liking and ranking of the target food, but decreased their consumption, whereas those whose parents had only received nutritional advice showed no significant increases in any of the measures.

These results suggest that parent-led graduated exposure techniques can be successfully used to increase their children's consumption of healthy foods.

3.3.3. Parent-led drug and alcohol education interventions

Beatty, Cross, and Shaw (2008) assessed their parent-focused, tobacco and alcohol education intervention using a school group randomisation procedure. 1201 parents of 10–11 year old children were randomised to the intervention that consisted of five sets of learn-at-home drug education materials and activities, or to the control group. Post-intervention questionnaires revealed that intervention group parents were more likely to have recently spoken to their child about the hazards of tobacco and alcohol, covering more of the essential topics outlined in the educational materials and to have reported higher levels of engagement when talking with their child, than control parents. However, no behavioural outcome measures were included, thus the relationship between improved communication and the children's alcohol or tobacco use remains unclear.

Jackson and Dickinson (2011) randomised 1183 non-smoking parents to either an anti-smoking parenting programme or a control group who received basic factsheets. Their original unpublished results found no significant group differences in smoking-specific outcomes in the children. Additional analyses reported in the current paper, however, revealed a dose–response pattern: greater parental engagement with the materials led to their children recalling more of the 14 behaviours targeted by the programme, and experiencing fewer pro-smoking risk factors (such as perceiving easy access to cigarettes, or feeling that there would be no negative consequences if their parents found them smoking) when interviewed both six months and three years following the initial intervention. This increased awareness of anti-smoking advice and pro-smoking risk factors were not, however, sufficient to change smoking behaviour: the children's likelihood to start smoking three years later showed no association with the amount their parents engaged with the study materials.

Parent-led educational interventions appear to be a potentially effective way of improving parent–child communication and increasing children's knowledge of substance-use associated risk, but in the studies described, such improvements did not lead to positive changes in behaviours.

3.3.4. Spouse-assisted lifestyle change interventions

Voils et al. (2013) conducted an RCT comparing a telephone-delivered spouse-assisted lifestyle change intervention, with treatment as usual, for 255 adult patients with high cholesterol. Their intervention included information about hypercholesterolemia and joint goal setting to improve the healthiness of their lifestyle. Cholesterol levels did not change post-intervention, however patients in the intervention group had significantly lower self-reported caloric intake than those in the control group. The intervention group also reported 10% longer, and 20% more frequent, physical activity sessions than the controls.

3.4. Carer-led symptom monitoring and management

Porter and colleagues' RCT (Porter et al., 2011) compared caregiver-assisted Coping Skills Training (CST) to an educational control, for patients with early stage lung cancer and their carers. Caregiver-assisted CST involved 14 telephone sessions, over 8-months, which taught caregivers how to help patients acquire and maintain coping skills over the illness trajectory. The control condition provided patients and caregivers with information about lung cancer and treatment options. Significant improvements in ratings of worst pain, physical and functional well-being, lung cancer symptoms, depression and self-efficacy were seen in the patients in both groups, with no significant differences between them. Thus in this study, caregiver-assisted CST was no more beneficial than providing patients and their carers with helpful information.

Keefe et al. (1996, 1999) conducted a three-arm RCT with patients with osteoarthritis of the knee, comparing spouse-assisted CST with conventional CST with no spousal involvement and also with a control group receiving a spousal support arthritis education package). At the end of the 10-week study period, patients in the spouse-assisted CST condition had significantly lower levels of pain, psychological disability, and pain behaviour, and higher scores on measures of coping attempts, marital adjustment, and self-efficacy, than controls. There were no significant post-intervention differences between those receiving spouse-assisted CST and conventional CST (Keefe et al., 1996) and after 12 months, patients in both CST groups had had lower levels of physical disability and higher levels of self-efficacy than the controls (Keefe et al., 1999).

Abbasi et al. (2012) compared a spouse-assisted multi-disciplinary pain management programme (SA-MPMP), consisting of seven weekly two-hour group sessions covering dyadic pain coping and couple skills, with a conventional patient-oriented pain management programme (MPMP) and standard medical care (SMC), for 36 patients with chronic lower back pain. All groups showed significant improvements in disability scores post-intervention, however at the 12 month follow-up, while both intervention groups' scores remained lower than baseline levels, those who received SMC had higher levels of disability than at the start of the study.

Taken together, these studies suggest that including carers in health monitoring and symptom management in long-term physical health conditions offers little benefit over and above that obtained through existing interventions or educational packages.

3.5. Carer-led interventions for mental health

Quayhagen and Quayhagen (2001) reported on two RCTs assessing 12 and 8 week versions of their caregiver-led cognitive stimulation intervention (CSI) for people with dementia. This involved hour-long sessions five times a week, focussing on memory, problem solving and communication skills. Controls included placebo (watching TV with a carer) and WLC. The first study ($N = 56$) showed improvements in immediate memory following the 12-week intervention, whereas the second ($N = 30$) found improved problem-solving after 8 weeks of CSI. In both studies, CSI groups also showed improved verbal fluency, whereas performance across all measures declined in both control groups.

An RCT of 156 dementia patients currently receiving the dementia medication Donepezil compared the effects of a carer-led reality orientation programme, with treatment as usual (Onder et al., 2005). The programme involved three 30-minute sessions per week, during which the caregiver directed attention to the current date, time and location. This was followed by discussing topics such as historical events, and exercises designed to target attention, memory and visuospatial skills. Following the 25-week intervention period, significant group differences were seen in the patients' cognitive functioning. Mini mental state examination (MMSE) scores and scores in the cognition subscale of the Alzheimer's disease Assessment Scale (ADAS-Cog) showed slight improvements in patients receiving the programme, compared to substantial decline in those receiving care as usual. Although such improvements were small, the authors argue that a difference in just one point in the MMSE is enough to substantially change the cost of caring for that patient.

There were no significant differences in caregiver burden, anxiety, or depression after the study (Onder et al., 2005) and a recent feasibility study by Milders, Bell, Lorimer, MacEwan, and McBain (2013) reported that delivering a cognitive stimulation intervention was beneficial not only to the dementia patient, but to carers as well.

Finally, a small single group pilot study assessed a parent-led cognitive behavioural therapy (CBT) programme for 26 young children with anxiety disorder (van der Sluis, van der Bruggen, Brechman-Toussaint, Thissen, & Bögels, 2012). This small single group pilot study found that parent-led CBT decreased both parent- and teacher-reported measures of child anxiety and behavioural inhibition, and increased mothers' use of positive parenting methods.

This group of studies suggests that carers are capable of delivering psychological interventions that lead to significant mental health improvements in those that they care for.

3.6. Screening delivered by carers

A two-part study by Paysse, Camejo, Hussein, and Coats (2004) assessed parents' reliability when delivering visual acuity testing to their children. In the initial stage, parents used an electronic visual acuity tester (EVA) to assess the visual acuity of their child ($N = 64$), with reliability assessed by comparison with an ophthalmic technician's results. In the second stage, 44 children were randomly assigned to either group 'A' who had their parents assess their visual acuity prior to the technician confirming the result, or group 'B' in which visual acuity was assessed using the full protocol by the technician. The researchers found that parents could not only reliably assess their child's visual acuity using the EVA, but that by doing so, the amount of time required with a qualified health professional was significantly reduced.

This study provides a positive example of carers reliably performing an essential part of an eye exam, which could set a precedent for including carers in other health check situations.

4. Discussion

4.1. Summary of findings

This review summarises the findings from a broad range of carer-led health interventions. Our initial aim was to identify successful intervention models that involved carers in screening, monitoring, or promoting health in adults with ID. However, with such a paucity of research in this field, more general examples were also sought. In non-ID populations, we found examples of carer-led interventions for health promotion, symptom monitoring and management, mental health and health screening procedures. Such diverse interventions and findings make generalisation difficult, however these studies do allow an insight into some aspects of carer-led interventions that do, and do not, seem to have a positive impact on health outcomes for the person being cared for. Such details may prove helpful for developing future carer-led interventions for people with ID and will be explored in more depth.

Of the three papers involving participants with ID, all assessed health outcomes following the use of a health diary or profile completed by carers. Despite such records being apparently well received by people with ID, their carers and health professionals, they were not used by a significant minority of those they were designed for and none of the studies found quantifiable improvements in health outcomes following their use (Lennox et al., 2008, 2010; Turk et al., 2010). With such poor adherence to these interventions, it is unclear whether this type of intervention is ineffective, or whether the reported lack of improvement in communication and health related outcomes reflects the fact that too few in the intervention groups

engaged with the materials. Authors for all three papers also noted that health outcomes from such interventions may take much longer to come to light than the timescale of these studies allowed (Lennox et al., 2008, 2010; Turk et al., 2010).

In terms of health promotion, a series of studies found that developing parenting and/or healthy lifestyle skills could lead to reductions in both BMI and the consumption of unhealthy foods in children (Golley et al., 2007, 2011; Magarey et al., 2011; Resnick et al., 2009). In two studies where parental knowledge of nutrition and health were assessed before and after the intervention, there appeared to be no significant improvement in what they knew (Resnick et al., 2009; Small et al., 2012). Nevertheless, in both studies, positive health outcomes were recorded in their children. One could therefore conclude that some other aspect of the interventions was leading to behavioural change.

These findings link well with those of Davison, Jurkowski, Li, Kranz, and Lawson (2013). Their paper reported on the process of including parents as equal collaborators in the development and evaluation of a family-led childhood obesity intervention and they explored factors impacting on the families' health from their perspective. In analysing their intervention, nutritional knowledge was not felt to be an important factor; rather the parents felt that they needed improved skills in social networking, advocacy, communication skills and conflict resolution. It was a lack of these skills rather than a lack of knowledge that they felt prevented them from providing a healthy lifestyle for their children. When considering the mechanisms that could lead to improvements in patient outcomes following carer interventions, it may therefore be that a focus on skills, rather than knowledge acquisition, is key.

Further evidence that improving knowledge is ineffective at modifying behaviour comes from a study assessing a parent-led tobacco education programme (Jackson & Dickinson, 2011). Variation in engagement with the study materials predicted children's knowledge, such that the children whose parents engaged most with the materials, had the highest knowledge of smoking risks and the lowest experience of particular risk factors. However, increased engagement with the programme had no impact on the child's likelihood to have started smoking three years later.

In terms of symptom monitoring and management, none of the studies included found that carer-led interventions were any more effective than existing interventions (Keefe et al., 1996, 1999; Porter et al., 2011; Voils et al., 2013). However, one argument for including carers in the healthcare of those they support is that it may help them to use health resources more appropriately. Although these studies suggest that using carers offers no additional benefit to the interventions that already exist, the results indicated that they were no worse. As such, training carers to deliver interventions may be a cost-effective way of ensuring that patients (such as those with severe ID) get the care they need.

We also found one promising example of health screening. Parents of children awaiting an optician's appointment were found to be capable of accurately and reliably assessing their child's visual acuity (Paysse et al., 2004). This is a positive example of carer input successfully reducing the need for clinician time, without negatively impacting on the reliability of the procedure. When considering the inclusion of carers in the health check process for people with ID, examples such as these may work as a precedent, highlighting the ability of carers to perform basic health screens, potentially increasing the effectiveness of interventions and health services.

For patients with dementia, we found that carers were not only capable of delivering interventions that led to positive improvements in the patient's cognitive functioning (Onder et al., 2005; Quayhagen & Quayhagen, 2001), but that delivering such interventions did not increase caregiver burden or anxiety (Onder et al., 2005) and in many cases, was felt to be beneficial to the carer as well (Milders et al., 2013).

4.2. Limitations of existing research

Several studies reported here were small scale, with short follow-up periods and varying levels of quality in their study control. Future studies need to be fully powered to test efficacy. As already noted, poor adherence to, or engagement with, interventions was a relatively commonly reported issue in these studies (Jackson & Dickinson, 2011; Lennox et al., 2010; Turk et al., 2010). Such variability in engagement with an intervention will inevitably impact on the results. Developing interventions in collaboration with carers may be one way of ensuring that the interventions are acceptable to those delivering them, and in turn, improve engagement (Davison et al., 2013).

A further limitation highlighted by Turk et al. (2010) was the high turnover of carers experienced by adults with ID in their study. The authors argued that this in itself highlighted a need for a patient-held health record, to ensure that necessary information was readily available, regardless of how well care staff knew the individual in question (Turk et al., 2010). In many of the examples we found from outside the field of ID, the carer in question was either a parent or spouse. While this may too be the case for some people with ID, others will rely on paid or voluntary care staff. The studies presented here have provided good support for being able to train carers to deliver health interventions, but in contexts where care staff may change frequently the acceptability of the intervention from carers' and patients' points of view, and time and financial costs involved in training new staff when required, would need to be incorporated into the research programme.

Participant attrition was a significant problem for many of the studies. The centre for evidence-based medicine argues that retention of less than 80% in a study reduces the quality of the study (Howick et al., 2011). Where it was investigated, for example by Jackson and Dickinson (2011) on their anti-smoking programme, differential attrition occurred, such that those who dropped out were more likely to be from the BME community, and to have high school education or lower, than those who chose to continue. Identifying factors involved in participants discontinuing with a study is important as such factors would need to be addressed and improved in order to make the intervention generalisable if successful.

A final limitation is that none of the studies included a cost analysis of the interventions presented. Using carers to deliver health interventions could save clinician time, and therefore money (Paysse et al., 2004). However, the cost effectiveness of such interventions will depend on the cost of training carers, and ensuring that they maintain reliability and accuracy in the intervention. In a context of frequently changing care staff, such costs could accumulate more quickly than in contexts where carers are more consistent.

4.3. Strengths and limitations of this review

As far as the authors are aware, this is the first review to consider carer-led health interventions as a means of improving the health of the people they care for, including those with intellectual disabilities.

Our intention was to focus on adults with ID, however a lack of existing research led to the inclusion of carer-led health interventions from a variety of patient populations, with different medical conditions, of differing age groups and in different settings. Such variation in the samples, the interventions themselves, and the outcome measures used to assess their efficacy, meant that a quantitative review of carer-led interventions was not possible. As such, over-arching conclusions concerning the efficacy of carer-led health interventions as a means of improving health are difficult to make.

Our research was time-limited, thus rapid review methodology was used. To reduce search time, we used just one database (Scopus), which may have resulted in missing some papers. This review also excluded studies that were not in English, and did not include interventions published in the grey literature. It is likely that other carer-led interventions exist, and are in use, but have yet to be evaluated.

Nevertheless, several successful models have been presented, and barriers to research, such as high carer turnover and a lack of engagement with the interventions have been identified. This review may therefore help future development of carer-led health interventions in general, not just in the ID population.

4.4. Directions for future research

With such a broad range of studies presented here, future research needs to aim to define the elements of carer-led interventions that are most likely to make a positive impact on a person's health. We need to establish how best to involve carers to ensure that high quality interventions are delivered, and that the interventions are acceptable to both those who are delivering, and those who are receiving them.

Identifying factors that would improve participant adherence and engagement with any given intervention is essential for improving the quality of future interventions. Including carers and the people they care for in the planning and development stages may be one way of producing interventions that are better adhered to.

Most crucially, it is essential that future interventions have a positive impact on health outcomes in the target population. Future studies must include sufficiently long follow up periods, to assess longer-term impacts, and health outcomes should be presented in ways that allow the reader to assess their impact in terms of noticeable changes for the patients, in addition to statistically significant results.

4.5. Conclusions

Carers have successfully delivered healthcare interventions, including screening, monitoring and health promotion, in a range of health settings. Nevertheless, for people with ID, there remains a lack of research in this area. With such varied interventions and outcomes found in the studies described in this review, it is hard to draw clear conclusions as how best to use carers to impact positively on the health of the person they care for in the ID community. In addition, engagement with the intervention appeared to be a common issue.

Involving carers and the people they care for in the research process may lead to better adherence to, and engagement with, carer-led interventions and should be an integral part of future research.

Conflict of interest

The authors declare that there are no conflicts of interest.

Funding

Appendix A

See Table A1.

Table A1
Summary of articles included in review.

Author/year	Caregiver group	Patient group	Intervention	Location	Study method	Level of evidence	Main findings	Category
Davison et al. (2013)	Family carers	Children with overweight/ obesity	Family developed, family-centred intervention for childhood obesity.	Upper State New York, USA	Pre-post cohort design. $N = 154$ at baseline, $N = 119$ at follow-up (77% retention).	4	Significant improvements in child's obesity, light activity, daily TV viewing and dietary intake. Parents reported higher self-efficacy in offering healthy lifestyles and better support for children's physical activity.	Health promotion
Voils et al. (2013)	Spouses	Married patients with one or more LDL-C $\geq$ 100 mg/ dL.	Spouse-assisted lifestyle change intervention	Durham, USA	2 group RCT: intervention or treatment as usual. $N = 255$ outpatients with LDL-C > 76 mg/dL and their spouses. Follow ups at 6 and 11 months ($N = 212 = 83\%$ retention).	1b	No significant differences in mean LDL-C levels at 11 months. Intervention group had significantly lower caloric intake, and intake of total/ saturated fat. Intervention group had 20% higher frequency, and 10% higher duration of physical activity than controls at 11 months. No changes in cholesterol medication usage.	Health promotion
Dovey and Martin (2012)	Parents	Children with sensory-related feeding problems	Parent-led graduated exposure	Leicestershire, UK	Single group pre/post design. $N = 17$ families.	4	Population-corrected height and weight increased significantly following the trial, but disproportionately, so that BMI changes did not reach significance. Intervention had greatest impact on number of fruit/veg the child would eat. No change in carbohydrate items, however these were the most well tolerated food items at baseline.	Health promotion

Small et al. (2012)	Parents	Young children with obesity	Parent-directed portion education intervention	USA	Pilot study. Single group pre/post design with $N = 45$ mothers and their 4–6 year old children. 30 dyads at post-test (67% retention)	4	Significant reduction in calories, saturated fat and carbohydrates served by mothers/consumed by children. No significant differences for protein. No improvements in parents' knowledge.	Health promotion
Moens and Braet (2012)	Parents	Children with overweight/obesity	Parent-led cognitive behavioural training	Flanders, Belgium	Pilot study, small scale RCT with 2 arms: parent-led cognitive behavioural training or wait-list control. $N = 50$ families with overweight children aged 6–12. Compared with reference group of $N = 36$ families.	2b	BMI reduced by 6 month assessment in both RCT groups, but only significant in the intervention group. At 12 months, all children in the RCT groups showed a decreased in BMI on average of 7%. Reference group BMI increased.	Health promotion
Golley et al. (2011)	Parents	Children with overweight/obesity	Parent-led, family focussed, child weight management programme	South Australia	Assessor-blinded, 3-arm RCT: parent skills + intensive diet and activity education (P + DA), parenting skills only (P) or 12 month wait-list control (WLC). $N = 111$ overweight, pre-pubertal children aged 6–9 years. Assessments at baseline, 6 and 12 months.	1b	Significant decrease in servings per day of 'extra' food, in both intervention groups only, maintained for 6 months post-intervention. No significant group × time differences. No significant differences in servings of fruit/veg/meat or substitutes/cereals and bread/dairy. Screen time reduced and active play increased in all 3 groups.	Health promotion
Jackson and Dickinson (2011)	Parents	Children who had not yet tried smoking	Parent-led anti-smoking programme	North Carolina, USA	2 group RCT: anti-smoking material ($N = 595$), or control group ($N = 588$). Follow up survey at 3 years post-intervention ($N = 1032$, 87% retention).	1b	Parents' engagement with anti-smoking socialisation predicted child's ability to recall anti-smoking advice and their exposure to smoking risk factors, up to 3 year post-intervention.	Health promotion

Table A1 (*Continued*)

Author/year	Caregiver group	Patient group	Intervention	Location	Study method	Level of evidence	Main findings	Category
Magarey et al. (2011)	Parents	Children with overweight/ obesity	Triple P parenting programme + healthy lifestyle intervention	Adelaide and Sydney, Australia	Single-blind RCT including P + HL (parenting skills – PPP, and healthy lifestyles training) vs. HL only (healthy lifestyles only). N = 169. By 24 months after baseline, for HL, N = 54 (21 boys) and for P + HL N = 52 (20 boys).	2b	Average 10% weight loss achieved, but no main group effect. No significant group effect when looking at parenting measures.	Health promotion
Resnick et al. (2009)	Parents	Children with overweight/ obesity	Parent-directed weight management programme	Massachusetts, USA	Pilot study of a two-arm RCT: parents received educational materials either through the post, or via interaction with a community health worker. N = 46 parents of overweight or obese children, aged 5–11 years. 91% retention.	2b	Non-significant trend towards increased parental knowledge about healthy living. Average hours watching TV was a significant predictor of BMI, and parent TV watching reduced post intervention. Intervention groups showed a significant reduction in BMI from an average of 94.1 to 90.6. No differences between those who received the healthy living training by mail or in person.	Health promotion
Beatty et al. (2008)	Parents	Pre-adolescent children	Parent-led drug education intervention	Perth, Western Australia	Group RCT with 3 conditions: intervention with choice of which materials to receive when, intervention with no choice, and a comparison group. N = 1201 parent completed questionnaires at baseline (of 1483 sent). 830 parents completed the follow-up measures. 69% retention.	2b	Intervention-group parents were more likely to have spoken with their children, more recently, to have engaged the child during the discussion and to have addressed the topics identified as being protective of children's involvement in tobacco and alcohol. The duration of talks about alcohol was longer than for parents in the comparison group. No differences between those who were offered choice in which materials they received when, and those that had no choice.	Health promotion

Golley et al. (2007)	Parents	Children with overweight/ obesity	Parent-led, family focussed, child weight management programme	Adelaide, Australia	Assessor-blinded, 3-arm RCT: parent skills + intensive diet and activity education (P + DA), parenting skills only (P) or 12 month wait-list control (WLC). $N = 111$ overweight, pre-pubertal children aged 6–9 years. Assessments at baseline, 6 and 12 months.	2b	BMI Z-score reduced by 9% in P + DA group, 6% in P group and 5% in WLC. 45% of children in the WLC group increased their BMI Z-score over 12 months, compared with 19% and 24% in the P + DA and P groups, respectively ($p = .03$). Only half of parents in the intervention groups attended 75% or more of the sessions. Waist circumference Z-score reduced in both intervention groups, but not in control group.	Health promotion
Wardle et al. (2003)	Parents	Children	Parent-led graduated exposure (daily introducing target food for 14 days)	London, UK	RCT with 3 conditions: exposure, information or control. $N = 156$ parents of children aged 2–6 years. Good retention (90%) but not a blinded study.	2b	Greater increases in liking, ranking and consumption of the 'target' vegetable from pre- to post-intervention occurred in the Exposure group than in either of the other two groups. Only the Exposure group showed significant increases across all three outcomes.	Health promotion
Milders et al. (2013)	Spouses or other primary (family member) caregiver	Adults with mild/ moderate dementia	Caregiver-led cognitive stimulation	Scotland	Feasibility/fidelity study. Measurements at baseline, 6 and 12 weeks. $N = 29$ dyads at start, 21 at end of study. 72% retention.	4	Caregivers were capable of delivering the cognitive stimulation, and did so adequately. There were no detrimental effects on the wellbeing of the caregivers themselves. Despite reporting some burden from having to do the exercises, most caregivers reported that they themselves also benefitted from them. Adults with dementia improved in their verbal fluency between the 8 and 16 week follow ups.	Mental health

Table A1 (Continued)

Author/year	Caregiver group	Patient group	Intervention	Location	Study method	Level of evidence	Main findings	Category
van der Sluis et al. (2012)	Parents	Young children with anxiety disorder	Parent-directed Cognitive Behavioural Therapy	Amsterdam and Maastricht, Netherlands	Pilot study. Single group pre/post design with N = 26 families of 4–6 year old children with anxiety disorder.	4	Children and parents reported significant reductions (medium effect size) in child's anxiety symptoms. No significant changes in externalising symptoms or social competence. Post intervention, mothers reported being significantly more likely to use positive reinforcement, modelling and reassurance responses to their child's anxieties, and significantly less like to use strategies that reinforced the child's dependence.	Mental health
Quayhagen and Quayhagen (2001)	Family carers	People with dementia	Caregiver-led cognitive stimulation therapy.	San Diego, USA	Case-control design using data from 2 previous RCTs: caregiver-led cognitive stimulation, placebo (watching TV/reading news with caregiver – with no discussion), wait-list control. N = 56 dyads (44 male patients). Results from 2 studies combined, without longer follow up data.	3b	Results showed improvement in immediate memory for patients in the first study, in problem solving in the second study, and in verbal fluency for patients in both studies, with decline in the respective control groups.	Mental health
Onder et al. (2005)	Family carers	People with dementia being treated with Donepezil	Caregiver-led reality orientation programme	Rome and Brescia, Italy	RCT with 2 groups: caregiver-led reality orientation programme, or control group. N = 156 (79 in intervention group). Follow up at 25 months. 88% participant retention.	1b-	Slight improvements for intervention group seen in MMSE and ADAS-Cog scores – compared to declines in the control group. No significant effects for behavioural/functional outcomes. No differences over time in caregiver burden.	Mental health

Lennox et al. (2010)	Family and paid carers	Adults with ID living in community settings	Comprehensive Health Assessment Programme (CHAP) and Advocacy Skills Kit (ASK) Diary	Greater Brisbane, Australia	4-arm cluster RCT: CHAP alone, ASK alone, CHAP + ASK, control-care as usual. 272 patients randomised, data from 242 analysed at end. 89% retention.	1b-	Increased health promotion, disease-prevention and case-finding in groups using the CHAP. CHAP led to more Pneumococcus & Hepatitis A vaccinations, hearing & vision tests and weight measurements. No improvements seen in the group using only the ASK diary.	Pre-checks/documentation
Lennox et al. (2008)	Family and paid carers	Adolescents with ID	Comprehensive Health Assessment Programme (CHAP) and Advocacy Skills Kit (ASK) Diary	Queensland, Australia	Pilot trial. $N = 30$ adolescents with ID, plus their parents, and 8 teachers. 26 adolescents attended a CHAP.	4	CHAP led to mean 5.2 health conditions being identified, and 1.4 health actions by the GP, per person. Teachers and students liked the ASK health diary, but it did not lead to increased communication.	Pre-checks/documentation
Turk et al. (2010)	Carers (paid/family)	Adults with learning disabilities	Implementation of a hand held health record	Greenwich and Bexley, UK	2 group RCT: personal health profiles ($N = 102$) or control ($N = 99$). GP surgeries were batch randomised ($N = 40$). $N = 163$ followed up after 12 months intervention. 81% retention.	1b-	A slightly greater increase in healthcare visits occurred over the year in the intervention group 0.6 (0.4–1.6) visits/year compared with controls. AWLD in PHP group reported more health problems at follow-up 0.9 (0.0–1.8). AWLD liked their PHP (92%) but only 63% AWLD and 55% carers reported PHP usage. Carers had high turnover (34%). Conclusions: No significant outcomes were achieved by the intervention.	Pre-checks/documentation

Table A1 (*Continued*)

Author/year	Caregiver group	Patient group	Intervention	Location	Study method	Level of evidence	Main findings	Category
Paysse et al. (2004)	Parents	Children	Parent-led visual acuity assessment	Texas, USA	Prospective experimental study with two phases. 1: N = 64 children had visual acuity tested using EVA, first by parents, then by technicians. 2: N = 44 children randomly assigned to group A: parent-led VA test or group B: technician performed full visual acuity check.	2b	Reliability of parent-determined VA was high (correlation with technicians scores was r = .91 for right and .81 for left eyes, with 93% of right eye parent scores and 85% of left eye parent scores within 0.11 logarithm of minimal angle of resolution (logMAR) units (i.e. within one line of vision) from technician's score. Parent pre-screen group required 66% fewer optotypes to right eyes and 68% fewer to left eyes, to determine VA, which markedly reduced clinician time.	Screening
Porter et al. (2011)	Friend or family member	Early stage lung cancer patients	Caregiver-assisted Coping Skills Training (CST)	North Carolina, USA	RCT with 2 arms: Care-giver assisted CST, or cancer education/support including caregiver. N = 233 patients + their caregivers. Follow up assessments N = 140. <80% follow-up	2b	Participants in both groups reported significant improvements over time in worst pain, physical and functional well-being, lung cancer symptoms, depression and self-efficacy. No significant intervention group differences. When dichotomising cancer stage, those with stage I benefitted most from the educational package, whereas those with Stage II and III cancers benefitted most from caregiver-assisted CST.	Symptom monitoring/ management

| Keefe et al. (1996) | Spouse | Patients with osteoarthritis of the knee | Spouse-assisted Coping Skills Training (CST) | North Carolina, USA | RCT comparing spouse-assisted CST, conventional CST and a control educational package. $N = 88$. 6 dropped out during course of study. 93% retention. | 1b- | The spouse-assisted CST condition had significantly lower levels of pain, psychological disability, and pain behaviour, and higher scores on measures of coping attempts, marital adjustment, and self-efficacy than patients in the AE-SS control condition after intervention. Compared to patients in the AE-SS control condition, patients who received CST without spouse involvement had significantly higher post-treatment levels of self-efficacy and marital adjustment and showed a tendency towards lower levels of pain and psychological disability and higher scores on measures of coping attempts and ratings of the perceived effectiveness of pain-coping strategies. There were no significant differences between spouse-assisted or conventional CST. | Symptom monitoring/ management |

Table A1 (*Continued*)

Author/year	Caregiver group	Patient group	Intervention	Location	Study method	Level of evidence	Main findings	Category
Keefe et al. (1999)	Spouse	Patients with osteoarthritis of the knee	Spouse-assisted Coping Skills Training (CST)	North Carolina, USA	Follow up of RCT comparing spouse-assisted CST, conventional CST and a control educational package. $N = 88$ at baseline, $N = 70$ at 12 month follow up. 79% retention.	2b	At 6-month follow-up, the spouse-assisted CST condition scored higher on measures of coping and self-efficacy than those in the AE-SS control group. At 6-month follow-up, patients who received CST without spouse involvement showed a significantly higher frequency of coping attempts and reported higher levels of marital adjustment than those in the AE-SS control group. At 12-month follow-up, patients in the spouse-assisted CST condition had significantly higher overall self-efficacy than those in the AE-SS control condition. In addition, patients in both the spouse-assisted CST and CST only conditions tended to show improvements in physical disability at the 12-month follow-up. There were no significant differences between spouse-assisted or conventional CST.	Symptom monitoring/ management

| Abbasi et al. (2012) | Spouses | Patients with chronic lower back pain | Spouse-assisted mulitdisciplinary pain management programme (SA-MPMP) | Tehran, Iran | 3 arm RCT. SA-MPMP, MPMP and standard medical care. $N=36$ at baseline, $N=29$ at 12 month follow-up. 80.5% retention. Underpowered. | 2b | SA-MPMP led to significant improvements in kinesiophobia and pain related rumination at 12 months, compared to standard medical care or standard MPMP. All groups improved in disability scores post-treatment, but all also rose up again at 12 month follow up. All improved on kinesiophobia measures (SA-MPMP significantly more than others) but by 12 month follow up had risen again (only slightly for SA MPMP group, but to levels higher than baseline for the other two groups). | Symptom monitoring/ management |

References

Abbasi, M., Dehghani, M., Keefe, F. J., Jafari, H., Behtash, H., & Shams, J. (2012). Spouse-assisted training in pain coping skills and the outcome of multidisciplinary pain management for chronic low back pain treatment: A 1-year randomized controlled trial. *European Journal of Pain, 16*(7), 1033–1043.

Alborz, A., McNally, R., & Glendinning, C. (2005). Access to health care for people with learning disabilities in the UK: Mapping the issues and reviewing the evidence. *Journal of Health Services Research & Policy, 10*(3), 173–182.

Backer, C., Chapman, M., & Mitchell, D. (2009). Access to secondary healthcare for people with intellectual disabilities: A review of the literature. *Journal of Applied Research in Intellectual Disabilities, 22*(6), 514–525.

Barr, O., Gilgunn, J., Kane, T., & Moore, G. (1999). Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland. *Journal of Advanced Nursing, 29*(6), 1482–1491.

Baxter, H., Lowe, K., Houston, H., Jones, G., Felce, D., & Kerr, M. (2006). Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice, 56*(523), 93–98.

Beatty, S. E., Cross, D. S., & Shaw, T. M. (2008). The impact of a parent-directed intervention on parent–child communication about tobacco and alcohol. *Drug and Alcohol Review, 27*(6), 591–601.

Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., & Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *Journals of Gerontology. Series A, Biological Sciences and Medical Sciences, 57*(7), M470–M472.

Cooper, S.-A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *British Journal of Psychiatry, 190*(1), 27–35.

Davison, K. K., Jurkowski, J. M., Li, K., Kranz, S., & Lawson, H. A. (2013). A childhood obesity intervention developed by families for families: Results from a pilot study. *International Journal of Behavioral Nutrition and Physical Activity, 10*(1), 3.

Dovey, T. M., & Martin, C. I. (2012). A parent-led contingent reward desensitization intervention for children with a feeding problem resulting from sensory defensiveness. *ICAN: Infant, Child, & Adolescent Nutrition, 4*(6), 384–393.

Emerson, E. (2011). Health status and health risks of the "hidden majority" of adults with intellectual disability. *Intellectual and Developmental Disabilities, 49*(3), 155–165.

Emerson, E., Baines, S., Allerton, L., & Welch, V. (2010). Health inequalities and people with learning disabilities in the UK: 2010. *Durham: Improving Health & Lives: Learning Disabilities Observatory*. Retrieved from: http://www.nepho.org.uk/uploads/doc/vid_7598_IHaL2010-3HealthInequality2010Summary.pdf.

Ganann, R., Ciliska, D., & Thomas, H. (2010). Expediting systematic reviews: Methods and implications of rapid reviews. *Implementation Science, 5*(1), 56.

Glover, G., & Ayub, M. (2010). How people with learning disabilities die. *IHAL: Learning Disabilities Observatory*. Retrieved from: http://www.lincs2life.org.uk/Libraries/Local/825/Docs/Executive/Jan%202012/How%20people%20with%20learning%20disabilities%20die.pdf.

Golley, R. K., Magarey, A. M., Baur, L. A., Steinbeck, K. S., & Daniels, L. A. (2007). Twelve-month effectiveness of a parent-led, family-focused weight-management program for prepubertal children: A randomized, controlled trial. *Pediatrics, 119*(3), 517–525.

Golley, R. K., Magarey, A. M., & Daniels, L. A. (2011). Children's food and activity patterns following a six-month child weight management program. *International Journal of Pediatric Obesity, 6*(5–6), 409–414.

Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013). *Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report*. Retrieved from: http://www.cabdirect.org/abstracts/20133132457.html.

Hollins, S., Attard, M. T., von Fraunhofer, N., McGuigan, S., & Sedgwick, P. (1998). Mortality in people with learning disability: Risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology, 40*(1), 50.

Howick, J., Chalmers, I., Glasziou, P., Greenhalgh, T., Heneghan, C., Liberati, A., et al. (2011). The Oxford 2011 levels of evidence. *Oxford Centre for Evidence-Based Medicine, 1*, 2011.

Jackson, C., & Dickinson, D. M. (2011). Anti-smoking parenting practices: Recall by and effect on children's risk of smoking after 3 years. *International Journal of Public Health, 56*(3), 263–270.

Janicki, M. P., Davidson, P. W., Henderson, C. M., McCallion, P., Taets, J. D., Force, L. T., et al. (2002). Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research, 46*(4), 287–298.

Keefe, F. J., Caldwell, D. S., Baucom, D., Salley, A., Robinson, E., Timmons, K., et al. (1996). Spouse-assisted coping skills training in the management of osteoarthritic knee pain. *Arthritis & Rheumatism, 9*(4), 279–291.

Keefe, F. J., Caldwell, D. S., Baucom, D., Salley, A., Robinson, E., Timmons, K., et al. (1999). Spouse-assisted coping skills training in the management of knee pain in osteoarthritis: Long-term followup results. *Arthritis Care & Research, 12*(2), 101–111.

Kerr, A. M., McCulloch, D., Oliver, K., McLean, B., Coleman, E., Law, J., et al. (2003). Medical needs of people with intellectual disability require regular reassessment, and the provision of client- and carer-held reports. *Journal of Intellectual Disability Research, 47*(2), 134–145.

Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 12*(1), 70–82.

Langan, J., Whitfield, M., & Russell, O. (1994). Paid and unpaid carers: Their role in and satisfaction with primary health care for people with learning disabilities. *Health & Social Care in the Community, 2*(6), 357–365.

Lennox, N., Bain, C., Rey-Conde, T., Purdie, D., Bush, R., & Pandeya, N. (2007). Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: A cluster randomized trial. *International Journal of Epidemiology, 36*(1), 139–146.

Lennox, N., Bain, C., Rey-Conde, T., Taylor, M., Boyle, F. M., Purdie, D. M., et al. (2010). Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 303–311.

Lennox, N. G., Rey-Conde, T. F., & Faint, S. L. (2008). A pilot of interventions to improve health care in adolescents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 21*(5), 484–489.

Magarey, A. M., Perry, R. A., Baur, L. A., Steinbeck, K. S., Sawyer, M., Hills, A. P., et al. (2011). A parent-led family-focused treatment program for overweight children aged 5 to 9 years: The PEACH RCT. *Pediatrics, 127*(2), 214–222.

Milders, M., Bell, S., Lorimer, A., MacEwan, T., & McBain, D. (2013). Cognitive stimulation by caregivers for people with dementia. *Geriatric Nursing, 34*(4), 267–273.

Moens, E., & Braet, C. (2012). Training parents of overweight children in parenting skills: A 12-month evaluation. *Behavioural and Cognitive Psychotherapy, 40*(01), 1–18.

NHS. (2008, April). *Clinical directed enhanced services (DES) guidance for GMS contract 2008/09*. NHS. Retrieved from: http://www.nhsemployers.org/SiteCollectionDocuments/DES_Guidance_cd_120209.pdf.

Onder, G., Zanetti, O., Giacobini, E., Frisoni, G. B., Bartorelli, L., Carbone, G., et al. (2005). Reality orientation therapy combined with cholinesterase inhibitors in Alzheimer's disease: Randomised controlled trial. *British Journal of Psychiatry, 187*(5), 450–455.

Paysse, E. A., Camejo, L., Hussein, M. A. W., & Coats, D. K. (2004). Parent-administered visual acuity testing: Is it reliable and can it improve office efficiency? *Journal of American Association for Pediatric Ophthalmology and Strabismus, 8*(4), 332–337.

Porter, L. S., Keefe, F. J., Garst, J., Baucom, D. H., McBride, C. M., McKee, D. C., et al. (2011). Caregiver-assisted coping skills training for lung cancer: Results of a randomized clinical trial. *Journal of Pain and Symptom Management, 41*(1), 1–13.

Puri, B. K., Lekh, S. K., Langa, A., Zaman, R., & Singh, I. (1995). Mortality in a hospitalized mentally handicapped population: A 10-year survey. *Journal of Intellectual Disability Research, 39*(5), 442–446.

Quayhagen, M. P., & Quayhagen, M. (2001). Testing of a cognitive stimulation intervention for dementia caregiving dyads. *Neuropsychological Rehabilitation, 11*(3–4), 319–332.

Redley, M., Banks, C., Foody, K., & Holland, A. (2012). Healthcare for men and women with learning disabilities: Understanding inequalities in access. *Disability & Society, 27*(6), 747–759.

Resnick, E. A., Bishop, M., O'Connell, A., Hugo, B., Isern, G., Timm, A., et al. (2009). The CHEER study to reduce BMI in elementary school students: A school-based, parent-directed study in Framingham, Massachusetts. *Journal of School Nursing, 25*(5), 361–372.

SciVerse Scopus Facts & Figures. (2010). Elsevier. Retrieved from: http://www.info.sciverse.com/UserFiles/2508.SciVerse.Scopus_Facts_Figures%28LR%29.pdf

Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 12*(1), 48–56.

Small, L., Bonds-McClain, D., Vaughan, L., Melnyk, B., Gannon, A., & Thompson, S. (2012). A parent-directed portion education intervention for young children: Be Beary Healthy. *Journal for Specialists in Pediatric Nursing, 17*(4), 312–320.

Straetmans, J. M., van Schrojenstein Lantman-de Valk, H. M., Schellevis, F. G., & Dinant, G.-J. (2007). Health problems of people with intellectual disabilities: The impact for general practice. *British Journal of General Practice, 57*(534), 64–66.

Thomas, R., & Barnes, M. (2010). Life expectancy for people with disabilities. *NeuroRehabilitation, 27*(2), 201–209.

Turk, V., Burchell, S., Burrha, S., Corney, R., Elliott, S., Kerry, S., et al. (2010). An evaluation of the implementation of hand held health records with adults with learning disabilities: A cluster randomized controlled trial. *Journal of Applied Research in Intellectual Disabilities, 23*(2), 100–111.

Underwood, L., McCarthy, J., Tsakanikos, E., Howlin, P., Bouras, N., & Craig, T. K. J. (2012). Health and social functioning of adults with intellectual disability and autism. *Journal of Policy and Practice in Intellectual Disabilities, 9*(2), 147–150.

van der Sluis, C. M., van der Bruggen, C. O., Brechman-Toussaint, M. L., Thissen, M. A. P., & Bögels, S. M. (2012). Parent-directed cognitive behavioral therapy for young anxious children: A pilot study. *Behavior Therapy, 43*(3), 583–592.

Voils, C. I., Coffman, C. J., Yancy, W. S., Jr., Weinberger, M., Jeffreys, A. S., Datta, S., et al. (2013). A randomized controlled trial to evaluate the effectiveness of CouPLES: A spouse-assisted lifestyle change intervention to improve low-density lipoprotein cholesterol. *Preventive Medicine, 56*(1), 46–52.

Wardle, J., Cooke, L. J., Gibson, E. L., Sapochnik, M., Sheiham, A., & Lawson, M. (2003). Increasing children's acceptance of vegetables: A randomized trial of parent-led exposure. *Appetite, 40*(2), 155–162.

Watt, A., Cameron, A., Sturm, L., Lathlean, T., Babidge, W., Blamey, S., et al. (2008). Rapid versus full systematic reviews: Validity in clinical practice? *ANZ Journal of Surgery, 78*(11), 1037–1040.

Webb, O. J., & Rogers, L. (1999). Health screening for people with intellectual disability: The New Zealand experience. *Journal of Intellectual Disability Research, 43*(6), 497–503.

Yang, Q., Rasmussen, S. A., & Friedman, J. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: A population-based study. *The Lancet, 359*(9311), 1019–1025.