

## REVIEW PAPER

# Obesity interventions for people with a learning disability: an integrative literature review

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## Abstract

**Aim.** This paper is a review of the effectiveness of non-surgical, non-pharmaceutical interventions designed to promote weight loss in people with a learning disability and how qualitative evidence on people's experiences and motivations can help understanding of the quantitative research outcomes.

**Background.** The health risks of obesity underline the importance of effective evidence-based weight loss interventions for people with learning disabilities as they are at increased risk of being overweight.

**Data sources.** Papers published from 1998 to 2009 were identified through searches of the Cumulative Index for Nursing and Allied Health Literature, Proquest, Medline (PubMed), PSYCHINFO databases, and the Cochrane Library.

**Review methods.** An integrative review method was used. Studies included were non-surgical or non-pharmaceutical interventions aimed at weight reduction for people with a learning disability. Synthesis of the findings related to study design, participants, types of interventions, outcome measures and participant perspectives.

**Results.** Twelve studies met the inclusion criteria. The most common research design was quasi-experimental pretest and post-test. Few researchers used a clinical trial approach, and there was only one predominantly qualitative study. Interventions were mainly focused on energy intake, energy expenditure or health promotion. Only a few studies incorporated behaviour modification approaches.

**Conclusion.** Nurses who work with clients with learning disabilities have a key role to play in the management of obesity. Future research needs to focus on qualitative studies of the perceptions of clients and their families, controlled trials investigating the effectiveness of interventions and their costs and sustainability, and longitudinal studies examining weight loss over time.

**Keywords:** integrative literature review, learning disabilities, nursing, obesity interventions

## Introduction

The focus of this paper is an integrative literature review of interventions designed to reduce obesity in people who have

learning disabilities. Many authors describe the 'obesity time bomb' that is evident in developed nations. For example, Mann *et al.* (2006) identify the increased prevalence of obesity in the United States of America (USA), and how

obesity is an important risk factor for premature morbidity and mortality. Similar issues are identified by authors in the United Kingdom (UK; Craig & Mindell 2008), Australia (Stanton 2009) and Canada (Bassett *et al.* 2008). Obesity is a major health problem as it is linked to illnesses such as cardiovascular conditions, diabetes, hypertension and various cancers (Marshall *et al.* 2003). The causes of the increase in weight in the general population are related to changes in diet and increasingly sedentary lifestyles. For example, Bradley (2005) reports that increased consumption of food outside the home, larger portion sizes and increases in average intake of salty, high calorie snacks and drinks, combined with less physical activity, have led to many more people becoming overweight and obese. The problem, however, appears more pronounced in people with learning disabilities, with authors such as Bhaumik *et al.* (2008), who conducted a large-scale paired-sample survey, confirming that weight problems for adults with learning disabilities are more common than in the general adult population in the UK. It is evident that nurses need to be particularly alert to the increased risk that people with learning disabilities have of a weight problem.

Reasons for the higher prevalence of obesity amongst people with learning disabilities are complex and have been associated with a range of genetic and environmental factors. For example, Allison *et al.* (1998) identified a number of genetic syndromes associated with obesity and learning disabilities, including Prader-Willi, Bardet-Biedl, Cohen, Carpenter, Borjeson and Down syndromes. However, Mann *et al.* (2006) suggest that, in general, having a learning disability may be associated with increased risk of obesity. Other explanations for this increased propensity are explored by Rimmer and Yamaki (2006) who indicate that environmental factors exert a powerful influence on the occurrence of obesity in people with learning disabilities. These environmental factors are described by Chapman *et al.* (2005), who identify that people with learning disabilities are more likely to be inactive due to barriers to accessing leisure and exercise facilities and the impact physical and intellectual impairment may have on the ability to take part in physical activities. In addition, lack of independent mobility and the ability to feed oneself, and the side effects of medication are added risk factors.

The health risks of obesity, together with the objective of regaining normal body weight, underline the importance of evidence-based weight loss interventions for all the population, and particularly for people with learning disabilities. A systematic review of weight loss interventions for people with learning disabilities is reported by Hamilton *et al.* (2007) and includes programmes focusing on energy-intake (nutrition), energy-expenditure (physical activity) or health promotion (education). However, Hamilton's review had several limita-

tions, including the fact that rather outdated studies were incorporated, with three being undertaken in the 1980s (Fox *et al.* 1984a, 1984b, Harris & Steven 1984 and Fox *et al.* 1985); in addition, five of the studies included in the present review were omitted (Ewing *et al.* 2004, Mann *et al.* 2006, Ordonez *et al.* 2006, Sailer *et al.* 2006 and Singh *et al.* 2008). There is no way of knowing if the omission of these five studies was because of poor quality, as no assessments of quality are reported by Hamilton *et al.* (2007). Other approaches to the management of obesity for people with learning disabilities include behavioural approaches, which focus on teaching self-control techniques and self-monitoring of food intake and weight, such as that reported by Singh *et al.* (2008). Finally, surgical interventions including gastric bypass surgery (Murray 2003), pharmacological treatment and use of orlistat, rimonabant and sibutramine are reported by authors such as Adam and Forth (2001). However, relatively few researchers have examined the effectiveness of weight loss interventions for adults with learning disabilities, and this was the impetus for the following review.

## The review

### Aim

The aim of the review was to answer the following questions:

- What is the effectiveness of non-surgical, non-pharmaceutical interventions designed to promote weight loss in people with learning disabilities?
- How can qualitative evidence on peoples' experiences and motivations help understanding of quantitative research outcomes?

### Design

An integrative literature review was carried out. Integrative reviews are described by Evans (2007) as being the broadest category of research reviews, combining the findings of a range of different research designs including those of qualitative and quantitative studies. The rise of the evidence-based practice agenda and prominence of systematic reviews based on the findings of randomized control trials have meant that to a large extent the findings of qualitative research have been at best marginalized or even excluded. Many authors, however, report that qualitative research methods allow in-depth exploration of important topics such as the views and priorities of consumers of healthcare services (For example in learning disabilities and mental health care, see Connor & Wilson 2006, Lathlean *et al.* 2007, Kurz *et al.* 2008, Vatne & Hoem 2008). In the present review, we

considered it important to include qualitative findings related to consumer identification and internalization of the aims and values of the obesity interventions, as this is thought to be crucial to the success of interventions.

### Search methods

A computerized search using the CINAHL (Cumulative Index for Nursing and Allied Health Literature), Proquest, Medline (PubMed), PSYCHINFO databases and the Cochrane Library was undertaken. Key words used to search for relevant literature included obese\*, overweight\* AND intervention\*, OR program\* OR evaluation\* OR effect\* AND learning disab\* OR learning difficult\* OR intellectual\* disab\* OR mental\* handicap\* OR mental\* retard\* in abstract. Hand searching of journals with a focus on learning disabilities was also undertaken. In addition, back referencing or citation searching of the selected studies was undertaken.

### Inclusion criteria

The following were adopted as the inclusion criteria:

#### Types of studies

- Randomized control trial
- Primary quantitative studies such as those with quasi experimental or similar design
- Any qualitative research design

#### Types of participants

- Those aged more than 16 years with a learning disability

#### Types of interventions

- All interventions aimed at reducing obesity in people with learning disabilities that did not include surgical interventions such as gastric bypass surgery or pharmaceutical treatment.

#### Types of outcome measures

- Impact of intervention on total body weight, body mass index (BMI) or waist measurement
- Experiences, feeling and beliefs of people with learning disabilities, their carers and healthcare professionals

Limits were set at studies published since 01/01/1998 and English language papers.

### Search outcomes

The search strategy identified 763 publications. Based on the inclusion criteria, and after eliminating overlaps and screening of titles, abstracts and keywords, ten publications were retained. After checking the reference lists of all included publications, two additional publications were included. Twelve were finally included in the review (See Figure 1).

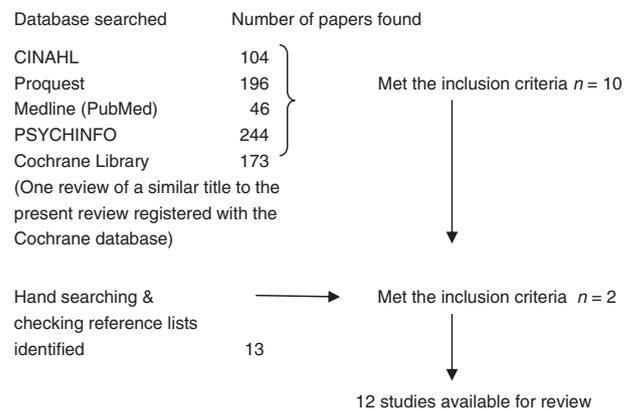


Figure 1 Results of search strategy.

### Quality appraisal and data extraction

Quality checks were performed on all the studies included in the review, with the first author selecting the abstracts for inclusion and doing the initial review. The second and third authors independently undertook quality checks using a purpose-developed checklist. The areas addressed in the quality assessment are given in Table 1. The scoring system involved one point being awarded for each of the criteria met, giving a possible maximum score of eight points. The scores of the studies ranged from four to eight, with only one paper achieving maximum points (Aronow & Hahn 2005). However, papers were not rejected based on quality appraisal scoring alone, as we considered that the rigour of the studies was important, but that new ideas for obesity management could also be explored. That is, we were interested in the study methods and the outcomes achieved. Thus, the main purpose of our quality assessment was to ensure that the studies conformed to usual research norms and were not unevaluated reports of clinical innovations.

The form used for data extraction had the headings given in Tables 2 and 3. That is, details of the study settings, samples, design, outcome measures and findings, including participant and family perceptions, were recorded on the data extraction form.

### Synthesis

Meta-analysis of the data was not feasible because although most of the studies had quasi-experimental pretest and post-test designs, there was a great deal of diversity in the interventions and outcome measures. An example of the synthesis approach used in the present review is reported by Taylor *et al.* (2004), who describe a three-stage method designed to synthesize the findings of qualitative and

**Table 1** Areas addressed in the quality assessment

	Score 0 = absent, 1 = present		Score 0 = absent, 1 = present
Assessment of quantitative studies		Assessment of qualitative studies	
Research questions/objectives/hypothesis are clear and appropriate	1	Research aims are clear and appropriate	1
Clear overview of intervention is given with use of appropriate outcome measures	1	Clear overview of intervention is given with use of appropriate outcome measures	1
Sample size is given	1	Number of participants is given	1
Randomization method is used in sample selection	1	Recruitment of participants is adequately described	1
Attrition rate from the intervention is recorded	1	Attrition rate from the intervention is recorded	1
Data analysis is adequately described and rigorous	1	Data analysis is adequately described and rigorous	1
Outcomes of the intervention are clearly described	1	Outcomes of the intervention are clearly described	1
Ethical issues are suitably addressed	1	Ethical issues are suitably addressed	1
Total possible scores	8		8

**Table 2** Study settings and samples

Study	Country and setting	Sample
Aronow and Hahn (2005)	Non-institutional settings in USA	201 adults with mild/moderate intellectual disabilities – 59% overweight/obese
Bradley (2005)	Supported living settings in the UK	Nine women with mild intellectual disabilities – 8 classified as obese
Chapman <i>et al.</i> (2005)	Day Centre in UK	Input group 38 adults with learning disabilities (64% overweight) Non-input group 50 adults with learning disabilities (97% overweight)
Ewing <i>et al.</i> (2004)	Family Practice Centre in the USA	92 with mild/moderate intellectual disabilities 97 normal learners
Mann <i>et al.</i> (2006)	Independent and supported living settings in USA	192 overweight/obese adults with mild/moderate learning disabilities
Marshall <i>et al.</i> (2003)	Day centres in UK	25 adults with a learning disability – majority overweight/obese ( $n = 17$ )
Ordonez <i>et al.</i> (2006)	Supported living in USA	22 male adolescents with Down syndrome. 27% overweight/obese
Podgorski <i>et al.</i> (2004)	Day Rehabilitation Centre in USA	12 older adults with mild to profound learning disability – 10 classified as obese/overweight
Poynor (2008)	Residential and supported living settings in the UK	19 adults with a learning disability and 7 support staff. Not stated if overweight
Rimmer <i>et al.</i> (2004)	Group homes and supported living settings in USA	52 adults with Down syndrome randomly allocated to intervention or control group – 69% obese
Sailer <i>et al.</i> (2006)	Human services centre in USA	Six people with a mild to moderate learning disability who were obese
Singh <i>et al.</i> (2008)	Own residence in USA	Seventeen-year-old obese adolescent with Prader-Willi syndrome

quantitative research. Such an approach involves initially reading and re-reading the papers. Three different activities are then undertaken, including considering the findings of quantitative studies. In the present study, the main focus was on extracting data on descriptions of interventions (including study design, samples and overviews of the interventions), outcome measures and evaluation of the effectiveness of interventions. The qualitative study included in the review was also examined to elucidate the participants' experiences and motivations concerning the intervention. To produce a narrative synthesis, the final stage of the synthesis involved integration of quantitative estimates of benefit with qualitative descriptions of feelings and beliefs about the intervention.

## Findings

### Study setting and samples

Twelve studies met the inclusion criteria and, of these, eight were conducted in the USA and four in the UK in a variety of settings including private residences, supported living and day centres, and group and residential homes. Sample sizes of the intervention groups ranged from 1 to 201 with a mean of 54 and a median of 25. A majority of the researchers reported using samples of people who were described as having mild-to-moderate learning disabilities. Two studies (Rimmer *et al.* 2004 and Ordonez *et al.* 2006) focused on people with Down syndrome and one concerned a young man with

Table 3 Interventions and outcomes

Study	Design	Description	Education or behavioural based intervention	Outcome measures	Findings
Aronow and Hahn (2005)	RCT with random allocation to a 'strong' and 'weak' intervention group	One year 'Stay Well & Healthy' programme 1st treatment group – ANP-conducted health assessment, 3 follow-up visits to monitor progress 2nd treatment group – Health risk appraisal by trained non-professional with printed feedback only	Education only	Health risks (including obesity) Health strengths Use of emergency services Life satisfaction and Community integration scales	Level of health risk decreased and level of health strengths increased significantly in both groups. (paired <i>t</i> -test = 0.141 <i>P</i> < 0.45)
Bradley (2005)	A pretest and post-test quasi experimental design *	One-year programme of healthy eating and exercise sessions delivered by a dietician. Ideas on how to achieve a balanced diet – tasting, food preparation, quizzes and games, and supermarket tours	Education only	BMI, Waist measurements Self-reported eating & exercise activities	4 lost 10% or more body weight. One lost 5% of body weight 8 out of 9 having breakfast regularly Increased consumption of fruit and vegetables Crisps, sweets and biscuits no longer snack items
Chapman <i>et al.</i> (2005)	A pretest and post-test quasi experimental design with a comparison group and 6-year follow-up (Chapman <i>et al.</i> (2008))	One-year 'Fighting Fit' activity programme with health information and support delivered by a healthy living coordinator who was also a physiotherapist. Local initiatives developed included health fairs, 'Wheels for All' and 'Shop, Cook & Eat'	Education only	BMI	The mean BMI in the input group decreased. The mean BMI in the non-input group showed a increase but these differences were not significantly different Six-year follow-up (Chapman <i>et al.</i> 2008) showed non-input group classified as obese or overweight increased by 45%. Proportions of in-put group classified as obese/overweight fallen by 67%. Differences were not statistically significant
Ewing <i>et al.</i> (2004)	A pretest and post-test quasi experimental design with a comparative group	8-week Health Education programme. Topics included nutrition, exercise, stress reduction, motivation to change and relapse prevention strategies	Education only	BMI, Cardiovascular fitness. Written test on consumption of fruit and vegetable and participation in exercise	Modest weight loss in small proportion of normal learners but no changes in mean of LD group. BMI did decrease by at least 0.75 for 18.5% of LD group. Positive changes in self report diet and exercise activities
Mann <i>et al.</i> (2006)	A pretest and post-test quasi experimental design	9-week health promotion programme. Topics included nutrition, exercise, stress reduction, communication, motivation to change and relapse prevention strategies	Education and behavioural	BMI, knowledge test, nutritional assessment and exercise assessment	Highly significant decrease in BMI (Paired <i>t</i> -test, mean change in BMI = 0.31, <i>P</i> > 0.0001) except for those with Down syndrome Self report diet and exercise improvements

Table 3 (Continued)

Study	Design	Description	Education or behavioural based intervention	Outcome measures	Findings
Marshall <i>et al.</i> (2003)	A pretest <i>and</i> post-test quasi experimental design	6- to 8-week health promotion programme. Modified Activate* materials including information on healthy eating and exercise	Education only	BMI	Significant decreases in mean BMI at onset 33.5 which fell to 31.9 (paired samples $t = 5.26, P = 0.001$ )
Ordonez <i>et al.</i> (2006)	A pretest <i>and</i> post-test quasi experimental design	12-week physical activity programme comprising of three 1-hour sessions each week on both land and water	Education only	BMI	Athropometric measures using Durmin-Womersley equation. Mean scores decreased from $31.8 \pm 3.7$ to $26 \pm 2.3\%$ ( $P = 0.021$ )
Podgorski <i>et al.</i> (2004)	A pretest <i>and</i> post-test quasi experimental design	12-week physical activity programme with 1-year follow-up	Education only	Fitness assessment and total body weight	Physical fitness scores improved after 12 weeks and were sustained at 12-month review. At 3 and 12 months, 4 lost weight and 7 gained weight
Poynor (2008)	Qualitative evaluation	6-week exercise programme and health promotion presentations delivered by a gym instructor and a range of health professionals. Visits to local supermarket	Education only	Questionnaire	All but two participants said they had enjoyed the programme and felt they had done well during the exercises. Completion of the homework tasks was viewed positively
Rimmer <i>et al.</i> (2004)	A pretest <i>and</i> post-test quasi experimental design	12-week fitness programme. 3 sessions a week lasting 45 minutes	Education only	Cardio-vascular fitness and BMI	Small but not statistically significant reduction of weight in intervention group [ $F(1, 44) = 7.96, P < 0.01$ ]
Sailer <i>et al.</i> (2006)	A pretest <i>and</i> post-test quasi experimental design	10-week weight loss programme	Behavioural and education	Total body weight	Three out of six participants achieved moderate weight loss
Singh <i>et al.</i> (2008)	Single case study with 3-year follow-up	Mindfulness-based health wellness programme delivered by parent	Behavioural and education	BMI	BMI lowered by 15 points

BMI, body mass index; RCT, randomized controlled trial; ANP, advanced nurse practitioner.

\*Pretest and post-test quasi-experimental design is defined as one that may have a control group but without randomized selection of sample.

Prader-Willi syndrome (Singh *et al.* 2008). Most were mixed gender groups, apart from Bradley (2005), who included only women and Ordonez *et al.* (2006) who had only men. All study participants were reported to be more than 16 years old, with one sample described as older adults (Podgorski *et al.* 2004), although 'old' was defined as more than 32 years of age. A summary of these findings is given in Table 2.

### Interventions and outcomes

The research design most frequently used in the studies reviewed was a quasi-experimental pretest and post-test design ( $n = 9$ ). Only one study had a clinical trial approach (Aronow & Hahn 2005), although the authors classified it as a preliminary feasibility study for a larger community-based randomized control trial (RCT). There was one predominantly qualitative interview study (Poynor 2008). Although Poynor's study included a questionnaire survey, these findings are not included in this review as they fell outside the protocol. The length of time over which the interventions were undertaken ranged from 6 weeks to 1 year, with one study having a 3-year follow-up (Singh *et al.* 2008) and another a 6-year follow-up (Chapman *et al.* 2008).

The types of interventions were largely a mixture of the categories reported by Hamilton *et al.* (2007). Some focused on nutrition (Sailer *et al.* 2006) or physical activity (Rimmer *et al.* 2004 and Ordonez *et al.* 2006), whereas one was a health promotion intervention, which included use of behavioural relapse prevention strategies (Mann *et al.* 2006). Another used mainly behavioural approaches and concentrated on teaching self-control techniques and self-monitoring of food intake (Sailer *et al.* 2006), and another considered the use of a mindfulness programme (Singh *et al.* 2008). However, while the remaining six studies included all the various elements of Hamilton's categories, most incorporated educational programmes designed to increase understanding of the importance of maintaining a healthy lifestyle. To achieve increased understanding, some studies involved activities designed to enhance participants' life skills. Such studies included, for example, visits to supermarkets, food preparation and food-tasting sessions (Bradley 2005), and health fairs and a 'Shop, Cook and Eat' initiative (Chapman *et al.* (2005).

A range of professionals apart from the researchers were involved in delivering the interventions, and included learning disability nurses (Marshall *et al.* 2003), advanced nurse practitioners (Aronow and Hahn (2005), staff from the community disability service providers (Mann *et al.* 2006), dieticians (Bradley 2005), health educators (Ewing *et al.* 2004), a healthy living coordinator who was also a physio-

therapist (Chapman *et al.* 2005), fitness trainers (Rimmer *et al.* 2004) and a therapist (Singh *et al.* 2008). Many interventions, however, involved a range of staff (Mann *et al.* 2006, Poynor 2008). Some also included involvement of participants' carers (Singh *et al.* 2008). However, only a few projects appeared to involve participants themselves in the design and direction of the initiative, with Bradley (2005) being the exception.

Ensuring the usability and acceptability of the programme materials and research tools was reported by majority of authors. For example, Bradley (2005) described how a pictorial diet sheet was developed for the study, whereas Aronow and Hahn (2005) used only 4th grade language in their material. Marshall *et al.* (2003) also reported how they modified materials produced for general use by the Northern Ireland Health Promotion Agency. Some authors also described how they overcame difficulties associated with the psychometric scales used in the study. For example, Aronow and Hahn (2005) developed visual analogue faces for self-rating of a general health status scale. Mann *et al.* (2006) also described how researchers read out assessment questions to participants and, when unsure of the responses, they clarified answers with participants' carers. Finally, Bradley (2005) identified particular difficulties with establishing weekly food intake and meal patterns of the participants and found that a show of hands was the most effective method of assessment.

The BMI was the most frequently used outcome measure, although researchers reported using measures of total body weight as an alternative (Podgorski *et al.* 2004, Sailer *et al.* 2006). Other physical outcome measures used included waist measurements (Bradley 2005) and measures of cardiovascular fitness (Ewing *et al.* 2004, and Rimmer *et al.* 2004). A number of authors also described use of self-report of eating and exercise activities (Bradley 2005, Mann *et al.* 2006), knowledge tests concerning food intake and exercise activities (Ewing *et al.* 2004) and use of psychometric scaling (Aronow and Hahn (2005).

Eight studies resulted in a reduction in participants' BMIs, with some researchers identifying the weight loss achieved as being statistically significant (Marshall *et al.* 2003, Rimmer *et al.* 2004, Mann *et al.* 2006 and Ordonez *et al.* 2006). Long-term follow-ups were done by Chapman *et al.* (2008) at 6 years and they found that the non-intervention group classified as obese had increased in weight by 45%, whereas the weight of the intervention groups had fallen for 67% of participants. These differences were, however, not statistically significant. Singh *et al.* (2008) also reported an overall weight loss at 3 years, with the BMI of the adolescent studied falling by about 15 points. Some, however, reported no change in mean weights (Ewing *et al.* 2004), and one that reported that

no weight loss was achieved for those with Down syndrome (Mann *et al.* 2006) or that only a very small weight loss was achieved (Sailer *et al.* 2006). Positive outcomes of the interventions included decreases in health risks (Aronow & Hahn 2005), increased consumption of fruit and vegetables, and other positive changes to diet (Ewing *et al.* 2004, Bradley 2005, Mann *et al.* 2006) and improvements in self-reported exercise levels and cardiovascular fitness (Ewing *et al.* 2004, Podgorski *et al.* 2004, Mann *et al.* 2006).

In the predominantly qualitative study, Poynor (2008) estimated client, carer and staff satisfaction with the intervention through questionnaires and interviews and reported mainly positive responses. For example, Poynor (2008) stated that all but two of the respondents enjoyed coming to the weight loss group. The two participants who left the course half way through reported that they felt irritated by the behaviour of the other participants. While some of the authors of the quantitative studies reported attrition rates, it is a strength of qualitative approaches that reasons for such attrition are investigated. It was stated explicitly at the onset of the programme described by Poynor (2008) that support staff and service users were expected to participate equally in the course. However, support staff participation varied, and it was found there was a link between this and client attendance and the likelihood that the homework set would be completed. It was thought that this verified the importance of the role of support staff in promoting health and fitness among people with learning disabilities. The importance of the involvement of support and carers is supported by a number of the authors of quantitative studies (Aronow & Hahn 2005, Mann *et al.* 2006 and Singh *et al.* 2008). A summary of these findings is given in Table 3.

## Discussion

The findings of many of the studies reviewed are encouraging, with a number of researchers reporting a reduction in participants' BMIs, and some identifying the weight loss achieved as being statistically significant. Other positive outcomes reported included decreases in health risks, increased consumption of fruit and vegetables, and improvements in self-reported exercise levels and cardiovascular fitness. Similarly, the findings of the qualitative study had mainly positive outcomes, with participants saying that they had enjoyed attending the fitness and health promotion sessions. However, these findings must be considered in the light of the limitations of the included studies.

Many of the limitations of studies reviewed have been alluded to in the course of describing them. For example, the relatively small sample sizes and varied characteristics of

samples clearly have an impact on the generalizability of the review findings. That some studies were classified as pilot studies (Podgorski *et al.* 2004, Aronow & Hahn 2005), the general lack of randomized controlled trials and absence of randomization in sample selection also raise concerns about the rigorous nature of the studies reviewed. It was also disappointing that only one primarily qualitative study was found to meet the inclusion criteria, which resulted in a lack of in-depth description of the views of study participants and their families. The general weakness of the evidence base of the review is reflected in the quality assessment scoring and by the fact that only one study achieved a maximum score. However, as indicated earlier, our intention was to include all studies that had a research framework and not to reject papers on their quality appraisal scoring alone. This was to gain insights into the ways in which interventions had been designed and delivered and thereby gain information on innovative approaches. Additionally, the infrequent use of randomized controlled trials was considered understandable due to the difficulties of adopting such approaches with people who have learning disabilities. Other design weaknesses of note relate to the relatively short time for which most interventions ran, the average being 20 weeks and some only lasting 6–8 weeks (Marshall *et al.* 2003, Ewing *et al.* 2004, Poynor 2008), and the lack of follow-up, apart from those described by Singh *et al.* (2008) and Chapman *et al.* (2008).

Additional concerns about the designs and procedures of the studies are that data analysis methods were not clear in the qualitative study reviewed. It would seem that a thematic content analysis approach similar to that described by Huberman and Miles (1998) was used in Poynor's (2008) study, but this is not obvious when reading the paper. Similarly, response rates were infrequently described. However, this is not an uncommon finding. For example, Badger and Werrett (2005) described the importance of reporting on response rates but found in a review of papers published in three nursing journals in 2002 that half did not report response rates. However, perhaps of more relevance to the present review is scarce reporting of attrition rates. This is important, as high rates of attrition could indicate poor levels of satisfaction with the intervention. As with response rates, attrition from the various interventions was seldom described, with only Poynor (2008) investigating why people left the programme. However, Sailer *et al.* (2006) reported that, to encourage attendance at the weekly meetings, a prize draw for regular attendees was introduced.

Another area of possible controversy concerns the outcome measures used in the studies. For example, predominant use

of BMI as an outcome measure is not without problems. Chapman *et al.* (2005) discussed some limitations of BMI measurements and identified that attempts to improve healthy lifestyles through exercise may increase BMI as fat is converted to muscle. A further difficulty is that interpretation of BMI is hindered because factors such as proportion of lean mass, gender and age are not taken into account. Jackson *et al.* (2009) raised a similar issue, making the point that BMI does not take account of differences in bone and muscle mass amongst ethnic minority groups. Thus, while few of the reports described the ethnic mix of the sample, none recorded that standard BMI calculations may not be appropriate for use for people from certain ethnic groups. Another surprising finding was that only Bradley (2005) recorded changes in waist measurements as an outcome measure. This is interesting, especially as waist-to-hip measurement is acknowledged as connected to the risks of developing myocardial infarction and type 2 diabetes (Yusuf *et al.* (2005). Other inherent weaknesses concerning the outcome measures the use of are self-reports of activities and diary records, which are open to participants giving inaccurate information.

Interestingly, whilst a majority of the reporters described the ethical procedures adhered to in gaining consent through reading out research consent forms to participants (Ewing *et al.* 2004) and asking carers' or guardians' permission for the person to take part in the study (Rimmer *et al.* 2004, Chapman *et al.* 2005), only Aronow and Hahn (2005) and Podgorski *et al.* (2004) reported seeking ethics committee approval. In contrast, Marshall *et al.* (2003) did not seek formal ethics approval as they viewed the study as an extension of existing services. Nevertheless, it is surprising, with the vulnerable nature of the sample population, that more mention of the ethical dimensions of the studies was not made. Another ethical dimension that was not really addressed in the studies reviewed is the dichotomy between respecting autonomy and freedom of choice of participants and the possible conflict with providing good care (Hooren *et al.* 2002). That is, should professionals accept that people with learning disabilities can make a conscious decision that they want to be overweight? A related issue is whether caregivers should intervene without taking into account the wishes of the individuals concerned, thereby undermining principles of self-determination. However, as Field (1996) discusses, what is probably more pertinent to this debate is ensuring that people with learning disabilities have the decision-making skills required for self-determination, and prevention of behaviours likely to be injurious to health. This is a topic that Singh *et al.* (2008) especially address in their review and evaluation of a mindfulness-based wellness

programme, introduced to increase self-control in eating activities of the individual concerned.

Another aspect that would have enhanced the utility value of the studies reviewed is an indication of the costs of the intervention. A number of authors reported funding sources of their study (Ewing *et al.* 2004, Podgorski *et al.* 2004, Rimmer *et al.* 2004, Aronow & Hahn 2005, Bradley 2005), and some equated this with the sustainability of the intervention. For example, Ewing *et al.* (2004) stated that their intervention had to be inexpensive and to mimic real life, as there would be no additional funding once the project ended. Conversely, Bradley (2005) and Poynor (2008) commented on the expense of their projects, with additional staffing being deployed for the duration of the project. Nevertheless, in general, they concluded that there was a gap in the evidence on the economic consequences of the interventions.

### Implications for nursing practice

The limitations of the studies reviewed do call into question the worth of many of the interventions examined. However, perhaps important to practitioners are considerations of the appropriateness of the intervention itself. The message from the majority of the studies reviewed is that motivation to continue with a healthy life style is allied to improving a client's knowledge and understanding. However, while improvements in knowledge about how to lead a healthy life are important, it was believed by some authors that improved knowledge alone is insufficient to change and maintain weight reduction (Field 1996). This is further borne out by the findings of Golden and Hatcher (1997), who described a seemingly contradictory relationship between nutritional knowledge and obesity in their study in that obese individuals possessed greater nutritional knowledge than did non-obese individuals. Some authors saw the use of behavioural interventions along with educational initiatives for healthy living as key to success (Bradley 2005). Here, the use of self-control techniques and self-monitoring of food intake described by Sailer *et al.* (2006), the use of a mindfulness programme reported by Singh *et al.* (2008) and relapse prevention strategies used by Mann *et al.* (2006) are of particular relevance.

A further consideration is the involvement of families and carers. Some of the authors of the studies reviewed described efforts to involve families and carers in the study (Mann *et al.* 2006, Singh *et al.* 2008). The importance of carer involvement is reinforced by the findings of Rimmer *et al.* (2004), who described how adults with learning disabilities who live in group homes and family households have considerably

### What is already known about this topic

- Obesity is a major health problem as it is linked to illnesses such as cardiovascular disease, diabetes, hypertension and various cancers.
- Obesity is more common in people with learning disabilities than in the general adult population.
- Reasons for the higher prevalence of obesity are complex, with a number of genetic syndromes associated with obesity and learning disabilities, but environmental factors also have a powerful influence.

### What this paper adds

- A majority of the studies reviewed focused on education-type interventions, with only a few describing use of behavioural interventions.
- Behavioural interventions are believed to be important to ensure success of a weight loss intervention for people with learning disabilities.
- The lack of controlled trials and very few qualitative studies in this area gives rise to future research imperatives.

### Implications for practice and/or policy

- Nurses have a key role to play in supporting and motivating carers and clients to achieve and maintain healthy lifestyle changes.
- Motivation to comply with suggested lifestyle changes will increase the more that carers and participants identify with an intervention programme and its values.
- There is insufficient evidence to guide nursing practice about what works for people with learning disabilities to maintain healthy weight.

higher rates of obesity than those living in larger homes. Similarly, Chapman *et al.* (2005) described how overprotection by parents can undermine the good practices instituted by professionals. Overprotection stems from the desire of parents to avoid the risks involved in taking part in what may normally be considered as low-risk activities, such as supervised swimming. Additionally, parents may underestimate their child's actual abilities. Also referred to by Bradley (2005) and Sailer *et al.* (2006) is the importance of including carers and participants themselves in the planning and delivery of programmes. Motivation to comply with suggested lifestyle changes will increase when carers and participants identify with the programme and its values. As Marshall *et al.* (2003) pointed out, advice given by profes-

sionals that a person needs to lose weight will have little impact if carers are not involved.

Messent *et al.* (1998) described variables that are of equal importance to changes in exercise levels and diet, behavioural and health education initiatives. One such variable is that of the limited opportunities that many people with learning disabilities have for community leisure pursuits. Messent *et al.* (1998) went on to describe how staffing constraints and unclear policy guidelines create formidable barriers to people with learning disabilities adopting more active lifestyles. Similarly, Chapman *et al.* (2005) gave further limitations, including resourcing, transport and expenditure restrictions, which many residential and day-care providers face. Adverse attitudes in society generally towards the normalization and integration of people with learning disabilities are clearly also an issue, and people with learning disabilities are disadvantaged on many fronts. One such disadvantage, as alluded to earlier in this paper, is that they are more prone to being overweight. This may be due to their learning disabilities, but may be compounded by physical difficulties, which make it harder to exercise. The studies reviewed here indicate how this may be further exacerbated by inadequate resources, lethargy or indifference to the situation by the general public, or even antagonistic attitudes towards people with learning disabilities when faced with integration policies in everyday life.

People with learning disabilities experience important health inequalities compared with the general population, including shorter life expectancy and higher levels of unmet health needs (Elliott *et al.* 2003). An accepted measure of health inequalities is the prevalence of obesity, which is known to be higher in adults with learning disabilities than in the general population. However, healthy living involves more than just losing weight. Physical activity levels, changes in diet and eating patterns, measures of emotional wellbeing and quality of life, and equality of access, are equally important when considering the 'whole life' needs of people with learning disabilities (Hamilton *et al.* 2007). It is in this context that nurses working in learning disabilities services can make a vital contribution. As Barber *et al.* (2008) state, considering the whole life needs of clients is central to the roles of nurses, and even more so for those working in services related to learning disabilities.

### Conclusion

While the evidence presented in this review will help nurses to decide how best to devise weight reduction interventions for people with learning disabilities, more work is required to develop user/carer-oriented and effective interventions. Finally, the review helps to identify future research agendas.

These should include more qualitative studies of the views and perceptions of clients and their carers, controlled trials to test the efficacy of the different treatment programmes, studies of the cost and sustainability of the various interventions, and longitudinal studies examining whether weight loss can be maintained over time.

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No conflict of interest has been declared by the authors.

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## Author contributions

AMJ and AC were responsible for the study conception and design. AMJ performed data collection and supervised the study. AMJ, AC and RR performed data analysis, were responsible for drafting the manuscript. AMJ and RR made critical revisions to the paper for important intellectual content. AC and RR obtained funding.

## References

- Adam O. & Forth W. (2001) Anti-obesity drugs: use, mechanisms and clinical importance. *International Journal of Clinical Pharmacological Therapy* 39(6), 232–238.
- Allison D.B., Packer-Munter W., Pietrobelli A., Alfonso V.C. & Faith M.S. (1998) Obesity and developmental disabilities: pathogenesis and treatment. *Journal of Developmental and Physical Disabilities* 10(3), 215–255.
- Aronow H.U. & Hahn J.E. (2005) Stay Well and Healthy! Pilot study findings from an in-home preventive healthcare programme for persons ageing with intellectual and/or developmental disabilities. *Journal of Applied Research in Intellectual Disabilities* 18(2), 163–173.
- Badger F. & Werrett J. (2005) Room for improvement? Reporting response rates and recruitment in nursing research in the last decade. *Journal of Advanced Nursing* 51(5), 502–510.
- Barber C., Garnham L., Lovell S., Camus H. & Persaud M. (2008) Galvanising the role of the learning disability nurse. *British Journal of Nursing* 17(4 Suppl.), S3.
- Bassett D.R., Pucher J., Buehler R., Thompson D.L. & Crouter S.E. (2008) Walking cycling and obesity rates in Europe, North America and Australia. *Journal of Physical Activities and Health* 5(6), 795–814.
- Bhaumik S., Watson J.M., Thorp C.F., Tyrer F. & McGrother C.W. (2008) Body mass index in people with intellectual disability, associations and service implications: a population-based prevalence study. *Intellectual Disability Research* 52(4), 287–298.
- Bradley S. (2005) Tackling obesity in people with a learning disability. *Learning Disability Practice* 8(7), 10–14.
- Chapman M.J., Craven M.J. & Chadwick D.D. (2005) Fighting fit? An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *Journal of Intellectual Disabilities* 9(2), 131–144.
- Chapman M.J., Craven M.J. & Chadwick D.D. (2008) Follow-up fighting fit: the long-term impact of health practitioner input on obesity and BMI amongst adults with learning disabilities. *Journal of Intellectual Disabilities* 12(4), 309–323.
- Connor S. & Wilson R. (2006) It's important that they learn from us for mental health to progress. *Journal of Mental Health* 15(4), 461–474.
- Craig R. & Mindell J. (eds) (2008) *Health Survey for England 2006, Latest Trends*. The Information Centre, Lifestyle Statistics, London.
- Elliott J., Hatton C. & Emerson E. (2003) The health of people with learning disabilities in the UK: the evidence and implication for the NHS. *Journal of Integrated Care* 11(3), 9–17.
- Evans D. (2007) Integrative reviews of qualitative and quantitative research. In *Reviewing Research Evidence for Nursing Practice* (Webb C. & Roe B., eds), Blackwell Publishing, Oxford, pp. 137–147.
- Ewing G., McDermott S., Thomas-Koger M., Whitner W. & Pierce K. (2004) Evaluation of a cardiovascular health program for participants with mental retardation and normal learners. *Health Education Behaviour* 31, 77–87.
- Field S. (1996) Self-determination instructional strategies for youth with learning disabilities. *Journal of Learning Disabilities* 29(1), 40–52.
- Fox R.A., Haniotes H. & Rotatori A. (1984a) A streamlined weight loss program for moderately retarded adults in a sheltered workshop setting. *Applied Research in Mental Retardation* 5, 69–79.
- Fox R.A., Burkhart J.E. & Rotatori A. (1984b) Physical fitness and personality characteristics of obese and non-obese retarded adults. *International Journal of Obesity* 8, 61–67.
- Fox R.A., Rosenberg R. & Rotatori A.F. (1985) Parent involvement in a treatment programme for obese retarded adults. *Journal of Behavioural Therapy and Experimental Psychiatry* 16, 45–48.
- Golden E. & Hatcher J. (1997) Nutritional knowledge and obesity of adults in community residences. *Mental Retardation* 35(3), 177–184.
- Hamilton C., Hankey C.R., Miller S., Boyle S. & Melville C.A. (2007) A review of weight loss intervention for adults with intellectual disabilities. *Obesity Reviews* 8(4), 339–345.
- Harris M. & Steven R. (1984) A pilot investigation of a behavioural weight control program with mentally retarded adolescents and adults: effects on weight, fitness and knowledge of nutritional and behavioural principles. *Journal of Rehabilitation Psychology* 29, 177–182.
- Hooren R.H., Widdershoven G.A.M. & Curfs L.M.G. (2002) Autonomy and intellectual disability: the case of prevention of obesity in Prader-Willi syndrome. *Journal of Intellectual Disability Research* 46(7), 560–568.
- Huberman M. & Miles M.B. (1998) Data management and analysis methods. In *Collecting and Interpreting Qualitative Materials* (Denzin N.K. & Lincoln Y.S., eds), Sage, Thousand Oaks, pp. 179–211.

- Jackson A.S., Ellis K.J., McFarlin B., Sailors M.H. & Bray M.S. (2009) BMI might be inaccurate assessment of obesity amongst minorities. *British Journal of Nutrition* 101(6), 879–885.
- Kurz A.E., Saint-Louis N., Burke J.P. & Stineman M.A. (2008) Exploring the personal reality of disability and recovery: a tool for empowering the rehabilitation process. *Qualitative Health Research* 18(1), 90–105.
- Lathlean J., Herbert L., Coldham T., East B. & Johnson T. (2007) User participation in mental health nurse decision-making: a co-operative enquiry. *Journal of Advanced Nursing* 60(2), 135–145.
- Mann J., Zhou H., McDermot S. & Poston M.B. (2006) Healthy behaviour change of adults with mental retardation: attendance in a health promotion programme. *American Journal on Mental Retardation* 111(1), 62–73.
- Marshall D., McConkey R. & Moore G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screening and health promotion activities. *Journal of Advanced Nursing* 41(2), 147–153.
- Messent P.R., Cookes C.B. & Longs J. (1998) Daily physical activity in adults with mild and moderate learning disabilities: is there enough? *Disability and Rehabilitation* 20(11), 424–427.
- Murray D. (2003) Morbid obesity; psychological aspects and surgical intervention. *AORN Journal* 78(6), 990–995.
- Ordonez F.J., Rosety M. & Rosety-Rodriguez M. (2006) Influence of 12-week exercise training on fat mass percentages in adolescents with Down syndrome. *Medical Science Monitor* 12(10), 16–19.
- Podgorski C.A., Kessler K., Cacia B., Peterson D.R. & Henderson C.M. (2004) Physical activity intervention for older people with intellectual disability: report on a pilot study. *Mental Retardation* 42(4), 272–283.
- Poynor L. (2008) Steps to fitness: a health and well-being pilot project. *Learning Disability Practice* 11(3), 10–16.
- Rimmer J.H. & Yamaki K. (2006) Obesity and intellectual disability. *Mental Retardation and Development Disabilities Research Reviews* 12, 22–27.
- Rimmer J.H., Heller T., Wang E. & Valerio I. (2004) Improvements in physical fitness in adults with Down's Syndrome. *American Journal of Mental Retardation* 109(2), 165–174.
- Sailer A.B., Miltenberger R.G., Johnson B., Zetocha K. & Hegstad H. (2006) Evaluation of a weight loss treatment programme for individuals with mild mental retardation. *Child and Family Therapy* 28(2), 15–28.
- Singh N.N., Lancioni G.E., Singh A.N., Winton A.S.W., Singh J., McAleavey K.M. & Adkins A.D. (2008) A mindfulness-based health wellness programme for an adolescent with Prader-Willi Syndrome. *Behaviour Modification* 32, 167–181.
- Stanton R. (2009) Who takes responsibility for obesity in Australia? *Public Health* 123(3), 280–282.
- Taylor J., Harden A., Oakley A., Oliver S., Sutcliffe K., Rees R., Brunton G. & Kavanagh J. (2004) Integrating qualitative research with trials in systematic reviews. *BMJ* 328, 1010–1012. (24 April)
- Vatne S. & Hoem E. (2008) Acknowledging communication: a milieu-therapeutic approach in mental health care. *Journal of Advanced Nursing* 61(6), 690–698.
- Yusuf S., Hawken S., Ounpuu L., Bautista M., Franzosi M., Commerford P., Lang C., Rumboldt Z., Onon C. & Lisheng L. (2005) Obesity and the risk of myocardial infarction in 27,000 participants from 52 countries. *The Lancet* 366(9497), 1640–1649.

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