Parent’s intentions to provide a healthy diet for children with a learning disability: The application of a revised Theory of Planned Behaviour

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Doctorate in Clinical Psychology

August 2013
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Assessed work: Thesis
Title of work: Parent’s intentions to provide a healthy diet in children with a learning disability: The application of a revised Theory of Planned Behaviour

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Word count for main body of thesis = 16, 614 (not to exceed 30, 000)
Chapter 1: WholeThesis Abstract

**Background:** Globally, childhood overweight and obesity, which impact negatively on an individual’s physical and emotional health, are increasing in prevalence. Children and young people who have a learning disability (CYPLD) have a higher incidence of obesity, overweight and underweight than typically developing children, and so weight related health problems add to their already more complex health needs. In Scotland, Heat Targets have been set to increase availability of childhood weight management interventions. Effective non-medical weight management interventions are available for typically developing children, addressing diet and including parents in treatment. There is a recognised need to develop evidence based weight management interventions for children and young people (CYP) who have a Learning Disability (LD).

**Aims:** This thesis has two parts. The first is a systematic review journal article which aims to answer the questions: ‘How effectively do single- and multi-component, systemic and direct, non-medical diet and exercise interventions promote optimal weight, amongst CYPLD?’ The second part, an empirical research project, aims to find whether both the Theory of Planned Behaviour (TPB) model in an original form, and an extended form which includes self-efficacy (SE), provide a statistically significant fit when applied to parents’ encouragement of healthy eating by CYPLD.

**Methods:** For the systematic review, five databases were searched. Included studies were required to have CYPLD as participants, who were receiving a non-medical
weight management, diet or exercise intervention, evaluated using weight or diet or exercise outcomes. Data from six articles were extracted and critically appraised using two tools. For the empirical research, parents (N=190) completed two online questionnaires one month apart, providing data relevant to both the original and expanded TPB models.

Results: The systematic review demonstrated evidence of some short-term impact on weight or improved fitness, following intervention. However, the studies were of mixed methodological quality. Limitations were poor study design, not adhering to recommended interventions or outcome measures or goals for treatment, and inclusion of underweight participants. The empirical study showed that both TPB models were a good fit with present data, and fit indices showed the original to be better than the extended model. Significant predictors of intention were not identified by either model.

Discussion: It was difficult to draw firm conclusions about effectiveness from the systematic review due to a lack of well-designed studies. However, multi-component, systemic interventions with adaptations to suit the needs of CYPID showed promise. The original TPB model was most suitable for informing practice in relation to parents’ intentions and encouragement of healthy eating by CYPID. Interventions that target parent’s attitude, subjective norm, perceived behavioural control, and self-efficacy, would not be recommended for this population. However, developers of interventions should consider special diets and mobility difficulties, and the clinical need to address weight and weight-related challenging behaviour amongst CYPID, as
well as to support parent’s in developing SE in managing these behaviours. Further research could develop improved measures for use with this population, and to identify alternative factors to predict parent’s encouragement of healthy eating by CYPID.

**Conclusion:** Literature and some policies highlight a clinical need to address weight amongst CYPID, and yet to date, effective interventions have not been adequately researched or developed for this population. The present research goes some way to establishing what is known already, indicating that a multi-component, systemic, adapted approach may be effective for this group. The TPB model is suited to researching parental encouragement of healthy diet by CYPID, although predictor variables have not yet been identified or recommended as targets for future interventions.
Chapter 2: Introduction

The purpose of this chapter is to provide additional relevant background literature which could not be included in the two journal articles, followed by some assistance to the reader in being navigated through the different parts of this thesis.

*Increased prevalence of unhealthy weight amongst children and young people who have a Learning Disability (CYPLD)*

The term Learning Disability (LD) (which refers to an IQ below 70, occurring before age 18, accompanied by impaired daily living skills; BPS, 2000) is specific to the UK. The term LD was used at an early stage during this research, for example, when seeking ethical approval, recruiting and collecting data. Therefore, the term LD has been used throughout this thesis, but an alternative term, Intellectual Disability (ID) has been used during the two journal articles, because these are intended for publication in international journals.

Children and Young People who have a LD (CYPLD), from a range of countries across the world, have consistently demonstrated a higher prevalence of obesity, over-weight and under-weight in comparison to typically developing peers (e.g. Emerson, 2009; Lin *et al.*, 2005; Maiano, 2011; Slevin *et al.*, 2003).
Measuring weight category

To provide some clarity about weight categories, there is international agreement about using Body Mass Index (BMI) (BMI = weight in kilograms/ height in metres squared), with agreed cut-offs for adults. The cut-off points determine whether an individual’s weight falls into the category of underweight, healthy weight (normal range), overweight or obese. BMI status is not static, and in children and young people BMI may change due to the effects of age and gender on growth, therefore adult cut-off scores would be misleading (NOO, 2011). Because of this, BMI percentiles, in which the BMI of an individual is compared with that of various available reference groups of same age and gender, are typically recommended for use with children and young people (CYP). For example, in the UK ‘UK90’ is recommended (NICE, 2006; SIGN, 2010), although these have now been superseded by updated charts (DOH, 2012), based on internationally recommended standards (WHO, 2006). Australian clinicians (NMHRC, 2013) similarly recommended using WHO (2006) charts. Clinical guidelines for Australia (NMHRC, 2013), New Zealand (NZ MOH, 2009) USA (US Preventative Services Task Force, 2010) and Canada (Lau et al., 2007) all recommend using US-CDC charts (Kuczmarski et al., 2002). BMI percentiles of 85 and 95 represent cut-off points for childhood overweight and obesity, and the second percentile marks the cut-off point for underweight (NOO 2011). An alternative approach to using BMI percentiles with cut-offs based on reference groups is using BMI with International Obesity Taskforce (IOTF) cut-offs (Cole et al., 2007). The IOTF approach has been widely used due to being internationally applicable (NOO 2011). This IOTF approach takes into account child age and gender, but rather than using a reference population, these are mapped onto
adult BMI thresholds, resulting in different rates of obesity than when using BMI percentiles with reference populations. IOTF was found to be less sensitive, including to the difference in BMI resulting from gender (Reilly et al., 2000). Currently clinical guidelines recommend not using IOTF in UK or Australia (SIGN, 2010; NHMRC, 2013), although this is still recommended by Canada whose guidelines are older (Lau, 2007). Using waist circumference as an alternative measure of weight is not recommended either, due to there being insufficient evidence to demonstrate it as a valuable tool when used with CYP, according to clinical guidance for Canada and the UK (Lau, 2007; SIGN, 2010).

Consequences of unhealthy weight

Health consequences for obese children include a greater risk from asthma, diabetes (Scottish Government, 2010), cardio-vascular disease (Friedemann, 2012), and low self-esteem (McCullough et al. 2009) resulting from stigma or bullying (Lawson, 2012). Given that 70% of all children who are obese are expected to become obese adults (Reilly, 2007), long-term risks for these children as adults include earlier mortality (WHO, 2011), cardio-vascular disease, diabetes, some cancers (WHO 2011), anxiety and depression (BPS, 2011). Obesity in CYPLD is associated with symptoms further to those experienced by typically developing peers who are obese, this being termed a ‘double stigma’ (Slevin et al., 2012). Symptoms for this group include additional fatigue, pain and social isolation (Rimmer et al., 2010). Parents or carers may additionally experience more difficulty in providing health and personal care when their child who has a LD is overweight or obese (De et al., 2008).
Underweight children are also at increased risk of early death (Herrington et al., 2001; WHO, 2011), often resulting from infections (Crawley, 2007).

*Risk factors associated with unhealthy weight amongst CYPLD*

SIGN guidelines (2010) highlight the necessity of researching influential factors in the development of childhood obesity. It may be over-simplistic to report that obesity is a result of an energy imbalance due to consuming more calories than are used. This view doesn’t take into approach the complexity of influential genetic, environmental, biological, and psychosocial systems on lifestyle behaviours (BPS, 2011). In addition to factors predicting unhealthy weight amongst typically developing children and young people (TDCYP), some additional factors increase the susceptibility of CYPLD to becoming obese.

*Parental Influence*

Having obese parents increases the risk of childhood obesity by six times (BPS, 2011). Parents can influence their child’s weight beyond the influence of genetics?, and some mechanisms include parental modelling of diet and exercise behaviours, feeding behaviours such as restricting or pressurising, parenting and discipline style such as using food as a reward (Skouteris et al., 2011), not recognising or being concerned by their child’s weight (Scottish Government, 2012b), and attachment relationship (Skouteris et al., 2012). The importance of family involvement in
treatment is recognised for all children (NICE, 2006; SIGN, 2010; Waters et al., 2011).

Similar to parents of typically developing children (Skouteris et al., 2011), the attitudes and motivations of parents/ carers affect the diet of people who have a LD (Smyth et al., 2006). People who have a LD are known to rely even more heavily on parents/ carers to provide a healthy diet (Fox et al., 1985; Hamilton et al., 2007), exercise (Melville et al., 2007), and access to the community (Marshall et al., 2003). People who have a LD may not understand long-term consequences of dietary decisions, therefore parents/ carers have a duty of care to provide support for people who have a LD to make informed choices (Marshall et al., 2003; Smyth et al., 2006). The literature suggest that parents of CYPLD may find themselves using food as a reward (Markella, 2011) or behavioural reinforcement (Bandini et al., 2005), and as compensation for their child having a LD (Markella, 2011). The additional guilt (Rimmer et al., 2007), stresses and demands placed on parents of CYPLD may mean that preparation of healthy meals to manage their child’s weight is not prioritised (Bandini et al., 2005).

*Socio-demographic factors*

A review of the literature (Maiano, 2011) found that gender, socio-economic status, and ethnicity did not affect risk of obesity amongst CYPLD. Increasing age did predict greater risk of obesity, however (Maiano, 2011). The contrast in prevalence
of obesity and overweight between CYPLD and TDCYP can be observed as early as age 3 to 5 years (Emerson, 2009).

*Other risk factors*

Although some literature suggest medications and the presence of specific genetic syndromes increase the risk of obesity amongst CYPLD (Bandini *et al.*, 2005), a review of the literature was inconclusive regarding the influence of genetic syndromes and medication use (Maiano, 2011). This same review reported that severity of LD was unlikely to affect the likelihood of obesity. The presence of some health conditions may also increase risk of obesity in CYPLD (Slevin *et al.*, 2012). CYPLD were found to consume a higher energy diet (Slevin *et al.*, 2012) and to be less active than typically developing peers (Slevin *et al.*, 2012; Frey *et al.*, 2008). Inactivity may result from a lack of social inclusion (Rimmer, 2007; Bandini *et al.*, 2005). Parents/ carers may have difficulty in trying to encourage a selective eater to eat more than a narrow range of foods (Schreck *et al.*, 2004). The child’s food choices may in turn be affected by their own mealtime behaviours (Bandini *et al.*, 2005). Both obese children (West *et al.*, 2009) and CYPLD (Bourke-Taylor *et al.*, 2009) display more challenging behaviour, including behaviours relating to eating. People who have a LD may be over-fed as an attempt to manage boredom, loneliness and problem behaviours (Melville *et al.*, 2007) and sad emotions (Rimmer *et al.*, 2007). CYPLD are more likely to have mobility problems, which may have limit their ability to engage in physical activity, the result being an increased risk of obesity (Bandini *et al.*, 2005).
What can be done to help CYPLD to have a healthy weight?

Psychologists are well-placed to provide or supervise a non-blaming, empathic approach to support families in contemplating diet and exercise changes (BPS, 2011; Yilmaz, 2011), which if handled insensitively may unhelpfully make people feel distressed or discriminated against (Lawson, 2012).

Scottish Heat targets (Scottish Government, 2012a) have been set to increase provision of childhood weight management interventions by 2014, the aim being to increase prevalence of healthy weight amongst CYP. Systematic reviews have taken place to establish what effective non-medical weight management interventions may involve for TDCYP (e.g. Waters et al., 2011). Based on evidence reviewed, UK guidelines for health professionals currently recommend a multi-component approach to non-medical treatment of childhood obesity, including diet, exercise, sustained behavioural change, and inclusion of parents/carers in treatment (NICE, 2006; SIGN, 2010). Despite the increased prevalence of obesity amongst people with a LD, effective weight management interventions for this group require to be researched and developed (SIGN, 2010). A systematic review has taken place to explore effective weight management interventions for adults with a LD (Jinks et al., 2011). This review identified twelve relevant studies, showing positive findings overall, but limitations included small sample sizes, use of quasi-experimental rather than randomised controlled design (RCT), and short-term interventions. Surprisingly, no systematic review had yet been carried out to establish effective aspects of non-
medical weight management interventions for CYPLD, and therefore the present systematic review was conducted. It was hoped that findings may be beneficial in the development of future effective interventions for this group.

The empirical research journal article continues in this theme of researching influential factors which predict healthy eating amongst CYPLD, with a view to informing the development of future interventions, so that parents may be better supported to encourage healthy eating by CYPLD. In Maiano’s (2011) review of factors influencing obesity amongst CYPLD, the author made recommendations that future research explores the influence of diet and parental influence. CYPLD have a less healthy diet (Slevin et al., 2012), and the above summary of the literature highlights that parents can influence children’s diet and exercise and weight. The present research study aimed to identify particular factors that predict parental encouragement of healthy eating by their son or daughter with a LD. This research has been underpinned by a Theory of Planned Behaviour (TPB) theoretical approach (Ajzen, 1991).

Navigating through this thesis

The main parts of the remainder of this thesis are the systematic review and empirical research journal articles. A bridging chapter, which connects the two journal articles, briefly describes the TPB model(s) and provides a rationale for the empirical research, stating the aims and hypotheses. This is followed by an extended methodology chapter, intended to capture additional information (ethics, recruitment, adaptation of original questionnaires) rather than replicating that within the empirical
research journal article (design, procedures, participants, validity and reliability of measures). Finally, all parts of this thesis will share the same final reference list and set of appendices. In combination, the focus of this thesis is to increase knowledge so as it may become possible to increase the prevalence of healthy weight, and therefore to improve physical and emotional health and lifespan, amongst CYPLD.
Chapter 3: Systematic Review

(See Appendix 1 for Author Guidelines: Journal of Pediatrics)

Non-medical obesity interventions for Children and Young People with Intellectual Disabilities

(In the version to be submitted for publication, author names and contact details will be added, the title will be reduced to the required 8 words using ‘youth’ rather than CYP, margins will be wider reducing page numbers, tables will be presented at the end of the article, and figures provided in a separate document).

Conflict of interest statement: There were no conflicts of interest, and no separate funding made available for this work. The main author completed this work as part-fulfilment of the Doctorate in Clinical Psychology Qualification, under supervision from co-authors.

List of key-words not in the title: Child, adolescent, overweight, evaluating treatments, diet, exercise, intellectual disability, systematic review.
ABSTRACT

Objective (and background)
This systematic review intended to answer the questions: how effectively do multi- and single-component, systemic and direct, non-medical diet and exercise interventions promote optimal weight, amongst children and young people who have an intellectual disability (CYPID)? This is in a context of increased prevalence of obesity in CYPID.

Study Design
Five databases were searched. Included studies (n=6) required that participants were CYPID, receiving a non-medical obesity treatment which was evaluated using weight or diet or exercise outcomes. Data from six studies were extracted and critically appraised based on two critical appraisal tools. A narrative approach was used to synthesise data.

Results
Included studies reported some short-term impact on weight or improved fitness following intervention. However, the studies were of mixed methodological quality.

Conclusions
Methodological flaws meant it was difficult to draw firm conclusions about effectiveness. This systematic review demonstrates a lack of well-designed studies.
Multi-component, systemic interventions with adaptations to suit needs of CYPID, show promise. Further research is needed, addressing limitations presented.
**Introduction**

Globally, childhood overweight and obesity, typically measured by Body Mass Index (BMI) (1), are increasing in prevalence (2). Obesity negatively impacts on the individual’s physical and emotional health, and reduces life span (2). Without intervention, obesity-related healthcare in the UK is predicted to cost the National Health Service (NHS) £9.7 billion annually by the year 2050 (3). In Scotland, a government ‘Heat 3’ target has been set to manage this problem by providing more weight interventions (4). National childhood obesity guidelines and practices are recommended to prioritise inclusion of people who have Intellectual disabilities (ID) (5, 6). UK (7, 8) and Australian (9) guidelines highlight the need to make interventions accessible to those with disabilities and recommend that further research is carried out to inform development of effective interventions for this group.

In the UK, a Learning Disability (LD) refers to an IQ below 70, accompanied by impaired daily living skills, occurring before age 18 (10). The term Intellectual Disability (ID) will be used instead of LD here, because of the international audience. In contrast to typically developing children and young people (TDCYP), no systematic review has yet been published in relation to obesity interventions for children and young people with an ID (CYPID). This is surprising, given the higher global incidence of obesity in this group (e.g. 11). For example, 36% of Scottish children who have an ID are obese (12), compared to 14% of TDCYP (13). Factors predicting behavioural patterns associated with obesity may differ for CYPID compared with typically developing children (11). For people with an ID, obesity related health problems add to already complex health needs (14). The increased incidence of obesity and consequent unmet health needs for this group, together with
policy recognition for the need to research and develop obesity interventions for the ID population (8), highlights that the present systematic review is timely and necessary. The aim was to answer the following: How effectively do single- and multi-component, systemic and direct, non-medical diet and exercise interventions promote optimal weight, amongst CYPLD? Single-component refers to diet or exercise or sedentary or screen time alone, whereas a multi-component intervention would target a combination of these behaviours. The term systemic here refers to interventions which include family and/ or school involvement, whereas direct refers to child alone interventions.

**Methods**

**Search strategy**

Databases were: Embase (from 1980), Eric (from 1966), Medline (from 1946), Psycinfo (from 1806), and Scopus (from 1960). Limits were not placed on dates, other than availability for each database, and searches took place on 29.5.13. Search terms (selected due to being broad and achieving highest numbers of articles during initial scoping searches), were used consistently with every database: ‘intellectual* disab* OR learning disab* OR mental* retard* OR developmental* disab* AND overweight OR obes* AND interven* OR program* OR educat* OR prevent* OR therap* OR treat* AND child* OR adolescent* OR parent* OR paediatric* OR pediatric’; (n = 619). Further studies (n = 6) were found by checking the reference lists from studies identified from databases, and more were obtained (n=5) following successful contact with main authors of some included studies.
Study selection

The titles and abstracts from the identified articles were checked for relevance against the inclusion criteria, and remaining articles were screened in full (n=36). Where there was uncertainty about whether to include a study based on the abstract, the full article was checked. Articles were assessed for suitability by two independent raters, and any differences were resolved following discussions. Six articles were deemed suitable for inclusion (Fig.1).

Inclusion criteria:

Included studies required all participants to be described specifically as having an ID (or equivalent term), and within the age range 0 to 18 years. Studies were included if they quantitatively evaluated a non-medical diet or exercise or other weight management intervention. Studies were included if outcomes were based on an indicator of weight change (e.g. BMI or body fat percentage), or a measure of diet or exercise. Inclusion required that methodology was adequately described. Studies were required to be available in English. ‘Grey literature’ and unpublished studies were included.

Exclusion criteria:

Studies where participants had Prader Willi or were tube fed were excluded, due to these groups differing in their diets to other CYPID. Individual case studies, literature reviews, and articles describing rather than evaluating interventions, were excluded.
Fig. 1. Flowchart, adapted from PRISMA flowchart (15), showing numbers of articles at each stage in the process of selecting studies for inclusion.

Data extraction

The following descriptive data were extracted and recorded (Table 1) for each included study: study (main author, year of publication, country where research took place, whether published, and a methodological quality rating), participants (numbers,
details about population recruited, age range, gender, baseline weight), comparison, study design, intervention (approach, intensity and frequency), measures and outcomes, maintenance and the research question with conclusion presented by author(s).

Attempts were made to contact authors to obtain any data not provided in their publications. Table 1 was intended to provide clarity on whether each study followed evidenced-based (16) and nationally recommended clinical approaches to treating childhood obesity (7, 8, 9, 17, 18, 19), as follows. Family and/ or school involvement (7, 8, 9, 16, 17, 18, 19), and a multi-component approach are recommended, (the latter meaning that interventions address multiple means of lifestyle change, such as diet, exercise and screen time) (7, 8, 9, 16, 17, 18, 19). Disabilities should be assessed and addressed (7, 8, 9) so that interventions are accessible to CYPID. Long-term input of at least 12 weeks (22) is suggested as being needed to bring about sustained behavioural change (7, 8, 9, 17, 18, 19), and follow-up measurements seem appropriate to measure whether change has been maintained (9). CYP require one hour of moderate exercise daily (7, 8, 9, 17, 19).

Quality assessment

Each included study was assessed for quality (20, 21), firstly using Scottish Intercollegiate Guidelines Network (SIGN) guidelines (20). This critical appraisal tool was selected because it had been seen as appropriate and used when reviewing similar effectiveness studies for obesity amongst TDCYP (8). The critical appraisal process involved checking SIGN’s Study Design Algorithm (20) to determine which
appraisal checklist, if any, may be appropriate. SIGN guidelines do not include a checklist for study designs such as ‘before and after study’ (22, 23, 24, 25), because these are viewed by SIGN as inadequate to provide evidence about efficacy of interventions (20).

Studies whose design matched a SIGN checklist (26, 27) were checked against this (Table 2) and then allocated a quality rating: majority of criteria being met (++), most (+), or almost no criteria being met (-). Due to the rigour of the SIGN method, all of the included studies either could not be critically appraised, or they were rated as (-). In order to gain information for this clinically important area where current research is limited, an additional tool was used to appraise all included studies. The latter tool, developed during a similar systematic review which explored obesity interventions for adults with an ID (21), will be referred to in the present research by the name of the first author (Jinks). The original Jinks tool examined eight domains, according to whether each was present (rated 1) or absent (rated 0). Whilst each domain may be more appropriately considered individually, the authors suggested summing scores in order to allocate each study a total score of up to 8. Adaptations were made to this tool for the present research, so as the focus shifted from description to critical appraisal of methodological rigour, and as a result, each study was examined using only seven domains, followed by being allocated a score of between 0 (poorer quality) and 10 (higher quality). Amended criteria are shown as headings (Table 3), these borrowing from other sources (20, 28, 29), such that suitability of control group and sample size, acceptability of attrition, and consideration to confounding variables are now included.
Table 3 additionally incorporated national childhood obesity recommendations (7, 8, 9, 17, 18, 19). The Jinks item relating to the appropriateness of the research question was interpreted based on guidelines (7, 8, 9, 19) which state an appropriate goal for overweight and obese CYP is to maintain rather than lose weight, due to the need for this population to grow. Any studies in which the goal was weight loss rather than maintenance were viewed as not having an appropriate goal, unless clear reasons were presented, such as participants being older teenagers and all having BMI of $\geq 99.6^{th}$ percentile (8). Having diet or exercise behaviour change as a goal was additionally viewed as appropriate (7, 17). The Jinks item relating to appropriateness of measures was similarly interpreted in relation to guidelines, so that any study measuring weight change outcomes using BMI percentiles which take into account age and gender, and using any recommended reference group, were viewed as appropriate (7, 8, 9, 17, 18, 19). Use of adult BMI which had not been translated into age and gender specific child BMI percentile using a reference population (7, 8, 17, 18), waist circumference (7, 8, 18, 19), and body fat measures such as skin-fold test (7, 8, 9, 18) with the exception of dual-energy x-ray absorptiometry (17) were either not mentioned, or specifically recommended against by these guidelines for use with CYP, and therefore viewed as inappropriate measures. Where diet and exercise measures were used either as well as or instead of weight measures, these required to be reported as valid and reliable (5), and at least one weight measure (in addition to diet or exercise measure if used) required to be appropriate in order to score a (1).

The ethics quality criterion was interpreted in three parts (See Table 3). The second item explored whether the study design allowed every participant, including from any control groups, to receive treatment. The third item, relating to ethics, was about
the aim of the study being safe, bearing in mind baseline weight of participants. Any study shown earlier to have weight loss as an inappropriate goal (Table 3) was checked against the baseline weights of participants (Table 1), and if any underweight participants were included in a weight loss intervention, this ethics item was marked as not appropriate.

Data synthesis

Heterogeneity in terms of interventions, measures and outcomes, and insufficient statistical information in some studies, meant that a meta-analysis was not appropriate. Extracted data were synthesised using a narrative approach.

Results

Details of excluded studies (n=29) are available on request from the first author (See Appendix 2). Six included studies (Table 1) were carried out in Canada, America, New Zealand, Spain, and Turkey, and children’s ages ranged from 8 to 18 years. Participant numbers ranged from 8 to 30, and studies typically recruited males and females, although two studies recruited only males (25, 27). The majority used a quasi-experimental before and after study design (22, 23, 24, 25), therefore these could not be critically assessed using a SIGN checklist (20). Those two studies assessed using the SIGN RCT checklist (20) both scored (-) (Table 2), and therefore every included study could be considered low quality in terms of methodological robustness, according to SIGN (20). Using the Jinks quality appraisal tool (Table 3) scores ranged from 0 (26) to 5 (22, 23) (10 = highest quality methodology, 0 = poorest).
<table>
<thead>
<tr>
<th>Study: Name of main author, Year; Country; whether published; Source; Appraisal rating</th>
<th>Participants: Participant number (n); Any additional information about sample; Any additional information about population (if required); Age range (years); Gender (Male = mal, Female = fem); Weight at baseline</th>
<th>Comparison; Study design</th>
<th>Intervention approach Are the following childhood obesity treatment recommendations (5, 6) included?</th>
<th>Intervention duration and frequency. Are these sufficient, according to childhood obesity treatment recommendations (5, 6)?</th>
<th>Measures and Outcomes (a) Follow-up measurements taken? (yes, no)</th>
<th>Research Question.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casey, 2010; Canada; Published; Sources: Medline database; SIGN (n/a); Jinks = 5 (22)</td>
<td>n = 8</td>
<td>Within subjects pre- and post- intervention; Quasi-experimental</td>
<td>(a) Family: No (b) School: No (c) Multi: No (d) Diet: No (e) Exercise: Yes. Swimming at 60-80% of maximum heart rate. (f) Screen: No (g) Behaviour: Yes. Modelling, praise and reward.</td>
<td>(a) Yes. 16 weeks. (b) No. 3 x 1 hour sessions each week.</td>
<td>Body fat % (Dual-Energy X-Ray Absorptiometry): Following intervention, the group’s body fat significantly increased from -0.3 to 4.5% (p = .039*)</td>
<td>Question: To measure effect of swimming training on body fat. Author’s Conclusion: Exercise intervention</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Year, Country</td>
<td>Published</td>
<td>Sources</td>
<td>n, Gender</td>
<td>Age Range</td>
<td>Multi</td>
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<tr>
<td>Davis, 2011</td>
<td>America</td>
<td>Published</td>
<td>Psychological databases, SIGN</td>
<td>n = 25</td>
<td>8 to 10;</td>
<td>No</td>
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<td></td>
<td></td>
<td></td>
<td>(no control group)</td>
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<td>Intellectual disability (mild to moderate range)</td>
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<td></td>
<td>Age range 8 to 10; Gender</td>
<td>16 mal, 9 fem; 5 underweight, 5 overweight, and 15 healthy weight.</td>
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<td></td>
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<tr>
<td>Hinckson, 2013</td>
<td>New Zealand</td>
<td>Published</td>
<td>Data available for n = 17</td>
<td>22 participants took part; Age range 10 to 18, Gender</td>
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Identical intervention took place in two schools.

(c) Multi: Yes

(d) Diet: Yes. Parent education as above. Child education on drinking more water, eating breakfast.

(e) Exercise: Yes. Varied exercises presented as games. Each session included 1 hour whole family exercise, then one hour child only exercise.

(f) Screen: Yes. Parent monitoring.

(g) Behaviour: 8 ‘motivation’ or ‘mind’ sessions. Parents and children were educated on modelling, triggers, goal setting, rewarding.

(h) Adapt: Yes. Children were given Velcro pictures to support choice of activity. Photographs or symbols were used to present dietary education. Adaptations to reflect individual needs of each child.

Interpretation based on effect sizes rather than p-values.

BMI: (calculated as body weight (kg)/height (metres squared)) ‘Trivial’ change following intervention: NS.

Waist circumference: (using a tape) ‘Trivial’ change following intervention: NS.

Fitness, using a walk test: Improvement following intervention interpreted as ‘possibly positive’, based on effect size.

Physical activity, screen time, and dietary habits were measured using a parent-reported questionnaire. All results using this measure were reported as statistically ‘unclear’, meaning that positive and negative possible changes were both possible.

Author’s Conclusion: Main changes following intervention were improved diet, exercise, and health (including weight), amongst young people with an Intellectual Disability.

Improving diet, exercise, and health (including weight), amongst young people with an Intellectual Disability.
true value ranges overlapped. Confectionary intake reduced.

(a) Yes, 24 week follow-up, showing improvement (participants could walk further)

**Numbers of children increasing or decreasing weight from each group.**

Five children from the intervention group lost an average of 12.25 pounds each. The sixth child gained 13.5 pounds. All six children from the control group each gained between 5 and 14 pounds. These descriptions of weight changes did not enable direct comparison between groups.

**Question:** Not explicitly stated.

**Author's Conclusion:** Author indicates that program was effective: "These statistics lead us to identify early childhood as the time to act in checking runaway weights".

**Sources:** Embase, Eric Medline and Scopus databases; SIGN (RCT checklist, miss items 2, 3 & 4) (-).

**Jinks = 0 (26)**

### Nelson, 1983; America; Published: Age range 9 to 17. Gender of each group: 3 mal, 3 fem; All 'overweight'.

n = 12 (n = 6 intervention, n= 6 control group); Intervention group (who showed most interest in intervention) compared with control group (who showed least interest in intervention); Non-randomised controlled trial design. Because study does not report randomisation took place.

**Both** Intervention and Control Groups were exposed to a treatment consisting of healthier school menu, parent education on health consequences, diet, modelling, and using non-food rewards in response to good behaviour. This was NOT the intervention being evaluated.

After the above input, the intervention group only received additional input:

1. **(a) Family:** Yes. Education on supporting child to follow exercise program.
2. **(b) School:** n/i
3. **(c) Multi:** Yes
4. **(d) Diet:** Yes. Dietary guidance was passed on to children through parents.
5. **(e) Exercise:** Yes. In addition to usual school exercise (swimming and gym)

(a) No. n/I on actual intervention, although pre-intervention treatment lasted 4 months.

(b) No. n/i.
for both groups, the intervention group were additionally trained to follow an individualised exercise program.

(a) No

(f) Behaviour: No
(g) Screen: No
(h) Adapt: No

Ordonez, 2006; Spain; Published; Sources:
Embase, Medline and Scopus databases; SIGN (n/a), Jinks = 2 (25)

n = 22 (no control group); 'Down's Syndrome'; Age range 15 to 17; Gender 22 mal, 0 fem; Author reports, based on BMI, 31.8% were overweight, and 27.3% obese at baseline. Weight category of remaining 40.9% not reported, so could be healthy or underweight.

Within subjects pre- and post-intervention; Quasi-experimental.

(a) Family: No
(b) School: No
(c) Multi: No
(d) Diet: No
(e) Exercise: Individually tailored program of land and water based activity, with intensity set according to heart rate.

(f) Behaviour: No
(g) Screen: No
(h) Adapt: No

(a) Yes. 12 weeks.
(b) No. 1 hour, 3 times per week.

Main outcome: Body Fat % (based on measurements of skin-fold thickness) reduced significantly from pre- to post-intervention (p = 0.021).

Additional pre- and post-treatment measures included: *Weight (kg), Fat free mass (%), *Fat mass (kg), Fat free mass (kg). *Significant improvement was shown in weight and fat mass (kg), both (p<0.05).

(a) No

Question: Study objective was stated as reducing fat mass % amongst adolescents who have DS, as a result of an exercise intervention. Author's Conclusion: Intervention was effective.

Ozmen, 2007; n = 30 (n=16 intervention group (who)

Intervention group only received:

(a) Family: No.
(b) No. 10 weeks.
Fitness: Shuttle run

Question: Is this exercise
| n/a = not applicable. n/I = not enough information. * = Significant at the 0.05 level. ** = Significant at the 0.01 level. *** = Significant at the 0.001 level. NS = Not significant. Scottish Intercollegiate Guidance Network (SIGN) (14) quality ratings: All or most criteria being met (++), some criteria being met (+), and almost no criteria being met (-).kg = Kilogram. RCT = Randomised controlled trial. mal = Male; fem = Female (Abbreviations as per AMA Manual of Style, as per author guidelines). |

<table>
<thead>
<tr>
<th>Turkey; Published;</th>
<th>Source:</th>
<th>Reference section of included study (23); SIGN (RCT checklist) (-), Jinks = 2 (27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mentally retarded (mild to moderate range); Age range 8 to 15; Gender 30 mal; 0 fem; Average adult BMI of both intervention and control groups at baseline were 19.5 and 18.0, and taking into account age-ranges and BMI-ranges, these figures suggested there were no underweight participants at baseline.</td>
<td>Received exercise intervention (b) School: Yes. School venue. times per week.</td>
<td>From pre- to post-treatment, significant improvement in fitness was shown by the intervention group (P &lt;0.05). There was no significant change in fitness for the control group.</td>
</tr>
<tr>
<td>(c) Multi: No</td>
<td>(d) Diet: No</td>
<td>% Body Fat: Skinfold test Neither group showed a significant change in body fat percentage following treatment.</td>
</tr>
<tr>
<td>(e) Exercise: Yes. Individually tailored program based on a heart rate. Varied activities.</td>
<td>(f) Behaviour: Yes. Modelling (how to perform interval training)</td>
<td>(g) Screen: No</td>
</tr>
<tr>
<td>(h) Adapt: No</td>
<td></td>
<td>Author’s Conclusion: Intervention was effective. (It improved fitness, but not body fat percentage, for this group).</td>
</tr>
<tr>
<td>intervention effective in: 1. Improving fitness and 2. Decreasing body fat percentage, in mentally retarded children?</td>
<td></td>
<td>(a) No</td>
</tr>
<tr>
<td>(b) School: Yes. School venue.</td>
<td>(c) Multi: No</td>
<td>(d) Diet: No</td>
</tr>
<tr>
<td>(e) Exercise: Yes. Individually tailored program based on a heart rate. Varied activities.</td>
<td>(f) Behaviour: Yes. Modelling (how to perform interval training)</td>
<td>(g) Screen: No</td>
</tr>
<tr>
<td>(h) Adapt: No</td>
<td></td>
<td>Author’s Conclusion: Intervention was effective. (It improved fitness, but not body fat percentage, for this group).</td>
</tr>
</tbody>
</table>
Table 2: Critical appraisal using SIGN RCT checklist (20)

<table>
<thead>
<tr>
<th>Study: Name of main author, Year, SIGN score</th>
<th>Clear research Question</th>
<th>Random assignment to groups</th>
<th>Adequate concealment method</th>
<th>Participants and investigators ‘Blind’ about treatment groups</th>
<th>Treatment and control groups similar pre-treatment</th>
<th>The only difference between groups is the treatment under investigation</th>
<th>Measures are standard, valid, reliable.</th>
<th>% drop out</th>
<th>Was ‘intention to treat’ analysis carried out?</th>
<th>Results similar across sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nelson, 1983, (-) (26)</td>
<td>No</td>
<td>n/a because non-randomised design. It is not clear whether families were allocated to the intervention group on the basis of interest/engagement.</td>
<td>n/a because non-randomised design</td>
<td>No: Groups differ in engagement in intervention.</td>
<td>No: Groups differ in engagement in intervention.</td>
<td>Yes: using weighing scales.</td>
<td>Not reported.</td>
<td>n/a, because drop out not known.</td>
<td>n/a – only one site.</td>
<td></td>
</tr>
<tr>
<td>Ozmen, 2007, (-) (27)</td>
<td>Yes</td>
<td>Yes.</td>
<td>Participants were randomly assigned groups, but the method for doing so has</td>
<td>No. Control group significantly fitter at baseline (p = 0.02). ANCOVA statistically</td>
<td>No. Control group significantly fitter at baseline (p = 0.02). Report that no</td>
<td>Yes</td>
<td>Not reported.</td>
<td>n/a, because drop out not known.</td>
<td>n/a – only one site.</td>
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</tbody>
</table>
not been reported. examined post-treatment differences between groups. children engaged in exercise initially, followed by contradictory report that control group continued to attend usual two hours of weekly physical activity. Not clear whether intervention group attended this too.

n/a = not applicable. Scottish Intercollegiate Guidance Network (SIGN) (14) quality ratings: Majority of criteria met (++), most criteria being met (+), and almost no criteria being met (-).
<table>
<thead>
<tr>
<th>Study: Name of main author, Year, total Jinks rating.</th>
<th>Table 3: Critical appraisal using Jinks scoring system (21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The study addresses an appropriate and clearly focused question. (1 = appropriate question according to clinical guidelines; 0 = no clear question or not appropriate according to clinical guidelines) (Adapted from SIGN checklist (20))</td>
<td>Clear overview of intervention and use of appropriate measures (Score 1 if yes for both parts)</td>
</tr>
<tr>
<td>Childhood obesity guidelines recommend measuring weight change using Child BMI (5, 6). Adult BMI, body fat, and waist circumference are not recommended for use with children. Diet or exercise measures should be reported as valid and reliable.</td>
<td>Was there a control group? (2 = yes, and both groups were similar at pre-treatment; 1 = yes, and differences between groups at pre-treatment were taken into account during analysis; 0 = no control group)</td>
</tr>
<tr>
<td>Sample size (for each group, if relevant) (Adapted from SIGN checklist (20))</td>
<td>Did sample size provide sufficient power (power = .8; alpha = .05; effect size = medium)? (Cohen, 1992) (1 = yes; 0 = no) (Description of Recruitment of participants)</td>
</tr>
<tr>
<td>Was attrition adequately low? (2 = &lt;5%; 5-20% = 1; &gt;20% = 0; 0 = not reported) (Adapted from Sackett et al. 2000)</td>
<td>Were potential confounders (variables associated with exposure and outcome) considered adequately in design and analysis? (2 = yes, mentioned and considered during analysis; 1 = mentioned but not considered; 0 = not mentioned (Adapted from SIGN checklist (20))</td>
</tr>
<tr>
<td>Addressing ethical issues (Score 1 if yes for all) (a) Parent informed consent (b) Study Design: Did all participants, including control group, receive treatment? (c) Is aim of study safe, bearing in mind baseline weights of participants?</td>
<td>Casey, 2010; Jinks = 5(22) (0) Research question clear but not appropriate (1) Combined score of both parts of this question, since (0) No control group. n = 8 (0) No Recruitment: Children attending ID schools were (2) Attrition not reported, but author contact confirmed there (1) Mention that diet and supervision may have (1) Combined score (a) Yes</td>
</tr>
<tr>
<td>Reference</td>
<td>Research question clear and appropriate.</td>
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<tr>
<td>Davis, 2011; Jinks = 5 (23)</td>
<td>(1)</td>
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<td>to seek to reduce fat when no evidence of BMI percentile &gt;99.6.</td>
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<tr>
<td>Hinckson, 2013; Jinks = 3 (24)</td>
<td>(0) Research aim clear but not appropriate, because maintaining rather than losing weight would suffice in this overweight and obese group, where there is no evidence of &gt;99.6th percentile BMI.</td>
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</tbody>
</table>
about child diet and exercise, were tools used in previously published studies. Bias introduced by parent’s rating, not an objective measure.

<table>
<thead>
<tr>
<th>Nelson, 1983; Jinks = 0 (26)</th>
<th>(0) Not made explicit.</th>
<th>(0) Combined score of both parts of this question.</th>
<th>(0) Groups differed and this was not acknowledged during analysis. n= 12, 6 in each group.</th>
<th>(0) No statistical analyses took place. Recruitment from a school. Criteria for inclusion not stated explicitly.</th>
<th>(0) This was not reported.</th>
<th>(0) No mention of confounding variables.</th>
<th>(0) Combined score</th>
</tr>
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<tbody>
<tr>
<td>(Implied aim of weight loss. Maintaining rather than losing weight would be sufficient for this overweight and obese group, where there is no evidence of &gt;99.6th percentile BMI.</td>
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<tr>
<td>(Yes) Intervention adequately described. Excessive description of treatment of both groups pre-treatment.</td>
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<tr>
<td>(No) Inadequate weight measures. Measures were mentioned such as a parent questionnaire, child height, girth, pulse rate, blood pressure, but no</td>
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<tr>
<td>Design &amp; analysis: Weight change reported following treatment, but no statistical analyses took place.</td>
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<tr>
<td>(a) No, parent ‘pledge’ to attend, not informed consent.</td>
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<tr>
<td>(b) No. RCT used without considering providing same treatment to control group.</td>
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<tr>
<td>(c) Yes. Overweight participants. No aim reported, but</td>
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results are presented in relation to these. Weight change in pounds was reported. BMI may not have been widely used at this time.

Ordonez, 2006; Jinks =32

| (0) Yes, clear objective stated, but not appropriate to try to reduce fat in this mixed weight population, when no evidence of >99.6th percentile BMI. | (0) Combined score of both parts of this question. | (0) No control group. n = 22 | (0) No Recruitment method not described. | (2) No drop out | (0) No mention of confounding variables. | (0) Combined score | (a) Yes | (b) Yes. Ethically appropriate design. | (c) No. Aim was to reduce fat mass, regardless that some of 40.9% of participants could have included some who were underweight. |

(Yes) Brief but clear intervention description. (No) Inadequate weight measures. Main outcome measure was body fat, and fat mass was also measured.

Criteria for inclusion not stated explicitly. Design & analysis: statistical comparison of before and after measures.
Ozmen, 2007; Jinks =2 (27)

(0) Research questions are clear, but not appropriate to try to decrease weight when no evidence of >99.6th percentile BMI.

(0) Combined score of both parts of this question.

(No) Insufficient information about baseline exercise participation for both groups, and whether this continued or was replaced by treatment for the intervention group. Otherwise, detailed treatment was described clearly.

(No) Fitness measure appropriate; Weight measure not suitable. Shuttle run described as valid and reliable measure of fitness. Body fat was used.

(1) Yes. Groups differed but this was considered during analysis. n=30 (n = 16 intervention group, n = 14 control group)

(0) No Recruitment was from two special schools.

Exclusion criteria: Limited mobility, musculoskeletal problems, hearing or sight problems, Down Syndrome, Autism.

(0) Drop out not reported. Attendance was 98% by intervention group.

(1) Mention that non-specified factors other than treatment could affect results, and that Down Syndrome differential physiology could contribute.

Design & analysis: statistical comparison of before and after fitness.

(1) RCT used without considering providing same treatment to control group.

(1) Yes. No evidence of underweight participants in this weight loss study.

For each item, ‘1’ is awarded if present, and ‘0’ if absent, then total ‘Jinks’ score created, with a higher score intended to represent better methodological quality. RCT = randomised controlled trial.
Inter-rater reliability

Three papers were independently rated using the Jinks criteria (22, 23, 24), as per Table 3. Inter-rater reliability was 91.6%. Any items about which there was disagreement were discussed and a consensus rating was agreed.

Effectiveness of components of interventions

The variety and diversity of the small number of studies do not allow outcomes to be reliably related directly to the content of interventions, so this summary is to be interpreted with caution.

Multi-component versus single component

Exercise as part of a multi-component approach along with diet (24, 26) and parental monitoring of sedentary time (24) were reported as effective, whereas exercise as part of a single-component approach was only found to be effective in two studies (25, 27) but not the third (22). There was insufficient evidence to draw a conclusion in relation to the effectiveness of behavioural strategies, and there were no diet only interventions included. Two (23, 24) of three studies were reported as effective when adaptations were made to suit CYPID, but the other study (22) was reported as ineffective.

Systemic (involving parents/ schools) versus Direct (child alone intervention)

It seems that interventions involving family or schools (23, 24, 26, 27) showed positive outcomes, whereas the non-systemic intervention (22) did not, with the exception of the
CYP with Down Syndrome, who lost weight despite a lack of family and school involvement (25). In terms of outcome measures, weight significantly reduced (25, 26) and fitness improved (23, 24, 27), but there was no improvement in body fat (22, 27), BMI, waist circumference, and diet and exercise habits (24). The study on CYP with Down Syndrome was an exception, reporting reduced body fat following exercise (25).

**Extent that bias may influence findings**

This section explores the impact of various areas in which methodological biases may have affected conclusions which can be drawn from included studies. The risk of selective reporting bias was not clear for the studies reviewed, because no research protocols were available.

**Multi-component versus single component**

*Appropriateness of Interventions*

The description of studies (Table 1) was compared with treatment approaches recommended by the National guidelines from several developed countries (7, 8, 9, 17, 18, 19). Two studies used the recommended multi-component approach to treatment. These focused on diet and exercise (24, 26) and parental monitoring of their child’s sedentary or screen time (24). The remaining four studies used single component interventions, with a focus on exercise only (22, 23, 25, 27). None of the six studies reported that participants received the required frequency or intensity: an hour of
moderate exercise daily. Two studies, both being single-component, lasted for an acceptable duration of at least 12 weeks (22, 25). In summary, both sets of interventions did not necessarily follow a recommended approach, based on clinical guidelines, and duration (the latter in particular for multi-component interventions), frequency and intensity may have been insufficient to bring about or detect change. As a result, the findings may have been biased, due to the difficulty of detecting possible positive changes under these conditions.

Appropriateness of outcome measures

Again, studies were compared with National clinical recommendations, this time in relation to measures of weight and diet and exercise change seen as most appropriate for use with CYP (7, 8, 9, 17, 18, 19). Child BMI percentiles, taking into account age and gender, are recommended (7, 8, 9, 17, 18, 19), so as to take into account the effects of child age and gender on growth. Those multi-component studies (24, 26) both used measures of child weight which were not appropriate, and so weight change may not have been accurately detected. Two single-component studies used appropriate measures (22, 23), whereas two did not (25, 27). Generally, measures of diet and exercise change (here measuring fitness) were valid and reliable for both multi-component (24) and single-component studies (23, 27). Only one study, which was multi-component and reported as effective, carried out a follow-up measure at 24 weeks (24). It is possible that other single- and multi-component studies may have missed possible longer-term changes due to not measuring at follow up.
**Appropriateness of research question**

Clinical guidelines recommend that maintaining rather than losing weight is an appropriate goal for most overweight and obese CYP (7, 8, 9) due to the need to continue to grow. Weight loss may be appropriate only when the BMI percentile is >99.6% and the child is older (8). None of the studies aimed to maintain weight, and both multi-component (24, 26) and three single-component (22, 25, 27) studies aimed to reduce weight when there was insufficient evidence to suggest participants required to do so. As a result, for both types of intervention, researchers may have been biased towards missing a positive finding where weight did not change. A combination of both multi- (24) and single-component (23, 27) studies aimed to improve diet or exercise, these being appropriate goals (7, 17).

**Study design**

The within subjects pre- and post-intervention designs of four studies (22, 23, 24, 25) can be associated with bias due to undetected confounding variables. This means that variables in addition to the intervention could change during this time, and it would not be possible to detect which of these resulted in changes measured, due to there being no control group. The possibility of missed confounding variables was acknowledged to be a limitation during two single-component studies (22, 23), whereas this possibility was not mentioned during one single-component study (25). However, the statistical analysis appropriately accounted for possible confounding due to age within one multi-component study (24). One single- (27) and one multi-component study (26) included a
control group, randomisation taking place but without details of method used, for the single-component study only. Both of these studies demonstrated differences between the characteristics of the control and intervention groups (26, 27), and therefore it was not possible to attribute any changes to the intervention alone.

Sample size, recruitment and attrition
Sample sizes were insufficient for all single- and multi-component studies. All but one single-component study (25) provided information on recruitment, and so the risk of sampling bias appeared generally low. Both multi-component studies (24, 26) did not report attrition, suggesting potential attrition bias, whereas the four single-component studies showed no drop out (22, 25), 7% drop out (23), and one (27) did not report attrition.

Baseline weights and ethical considerations
In both multi-component intervention studies, all participants were either overweight or obese (24, 26), and this was also the case for two of the single-component intervention studies (22, 27). Amongst the other two single-component intervention studies, the baseline weight of 40.9% of participants was not reported in one study (25), and participants of mixed weight were reported to include 15 healthy weight and 5 underweight participants in another (23). Inclusion of healthy and under-weight participants in weight loss interventions may have resulted in smaller weight changes, which could be misinterpreted as interventions being ineffective, and generalizability to
overweight and obese populations being reduced. Including underweight children as participants in treatments where they might lose weight also raised ethical concerns. No study reported explicitly whether harm had unintentionally occurred or been considered as a result of treatment, despite clinical guidelines recommending this practice (8, 9, 19). Finally, amongst those two studies with a control group, one being single-component (27), and one being multi-component (27) in treatment approach, neither reported ensuring that control groups received treatment at a later date.

**Systemic (involving parents/schools) versus Direct (child alone intervention)**

**Appropriateness of Interventions**

As before, the description of studies (Table 1) was compared with treatment approaches recommended by the National guidelines from several developed countries (7, 8, 9, 17, 18, 19). No study explicitly reported using a particular theoretical approach, but behavioural change appeared to underpin interventions in every study. Whilst not described as such within the studies, a systemic approach describes interventions in which families and / or schools are involved in treatment. Recommendations to involve families in treatment (7, 8) were adhered to by two studies (24, 26), and school involvement was reported by three (23, 24, 27). Three studies additionally reported making appropriate adaptations suited to CYPID (22, 23, 24).
Appropriateness of outcome measures

National clinical recommendations in relation to suitable measures for this population (7, 8, 9, 17, 18, 19), were again considered. Those studies using a systemic approach used a combination of appropriate (23) and inappropriate (24, 26, 27) measures of child weight, similar to weight measures during interventions aimed at children alone (22 being appropriate whereas 25 was not). Only systemic interventions used fitness measures, and these were generally objective, valid and reliable (23, 24, 27). Only one study, systemic in approach, demonstrated a positive long-term outcome due to including a follow-up measure (24), whereas possible long-term changes may have been missed following remaining systemic and direct interventions.

Appropriateness of research question

As before, based on clinical guidelines about appropriate weight change goals for CYP (7, 8, 9), no study aimed to appropriately maintain weight. Three systemic studies (24, 26, 27), and two in which children alone were treated directly (22, 25), aimed to reduce weight when there was insufficient evidence to suggest participants required to do so. As a result, where weight did not change, researchers may have been biased towards missing this positive finding. All of the studies which appropriately aimed to improve diet and exercise (7, 17) used a systemic approach (23, 24, 27).
**Study design**

Both studies in which there was a control group (26, 27), used a systemic approach. Neither demonstrated adequate randomisation, and only one (27) took into account the differences between control and interventions groups during analysis. Remaining studies had no control group, this increasing risk of undetected confounding variables, amongst both systemic (23, 24) and direct (22, 25) approaches. One systemic (23) and one direct study (22) mentioned confounding as a possibility. Whereas the additional systemic study with no control group adjusted data for age during analysis (24), the further direct study did not report confounding as a possibility (25).

**Sample size, recruitment and attrition**

Sample sizes were insufficient for all systemic (23, 24, 26, 27) as well as all direct intervention studies (22, 25). All but one direct study (25) provided information on recruitment, and so the risk of sampling bias appeared generally low. Both direct intervention studies reported no drop out, whereas systemic studies did not report attrition (24, 26, 27) or reported 7% drop out (23).

**Baseline weights and ethical considerations**

Baseline weights were suitably overweight or obese for participants of three of the studies using a systemic approach (24, 26, 27), and one direct approach study (22). However, the baseline weight of 40.9% of participants was not reported in one direct approach study (25), and participants of mixed weight were reported to include 15
healthy weight and 5 underweight participants in a further systemic study (23). Both studies with control groups (26, 27) were systemic in approach, and they did not report ensuring that control groups received treatment at a later date.

**Discussion**

*Patterns that emerged across all six studies*

The small number of included studies (n=6), all having too small sample sizes, suggests this is an under-researched area. Authors have generally reported positive outcomes from all but one (22) of these intervention studies. However, none were adequately methodologically robust according to SIGN criteria (20), and the highest ratings were 5 (22, 23) (where 10 indicates highest methodological rigour using an adapted critical appraisal tool (21)). Areas where the studies were rated lower included having designs in which there was either no control group or differences between control and intervention groups which were not accounted for during analyses; interventions which did not follow clinical recommendations in terms of having insufficient frequency, intensity or duration; not measuring outcomes at follow up; using weight outcomes not recommended for use with children; and having weight loss as a goal when this is not recommended clinically. In terms of ethical quality criteria, studies scored lower when underweight participants were expected to lose weight. No included study offered control groups treatment, and no study reported unintentional harm.
**Multi-component versus single component**

In terms of following clinical guidelines, only two of six studies followed a recommended multi-component approach (24, 26), both of these reporting positive outcome (whereas outcomes were mixed amongst single component studies). This improvement in fitness following multi-component intervention was maintained when measured at follow up (24). This is despite a bias towards missing positive findings amongst multi-component studies, due to their insufficient duration, and use of less appropriate weight measures. Single component studies were less likely to account for confounding variables during analysis, and their sampling risk may have been higher as indicated by not reporting recruitment (25). Baseline weights were more appropriate amongst multi-component interventions (24, 26). However, there was a greater risk of attrition bias amongst multi-component interventions (24, 26).

**Systemic (involving parents/ schools) versus Direct (child alone intervention)**

Recommended systemic studies were reported as effective (23, 24, 26, 27), whereas findings were mixed amongst non-systemic interventions. Amongst those three studies reporting making adaptations to suit CYPID, two were reported as effective (23, 24), suggesting their adaptations may be usefully applied to future interventions. Only a systemic study had an appropriate fitness goal (23), or used measures of fitness (23, 24, 27), these all being valid and reliable, and indicative of positive findings. The only study including a follow-up measure which indicated maintained improvement (24), and adjusting analyses taking into account the possibility of age as a confounder, was
systemic in approach also. Attrition bias appeared more problematic amongst systemic compared to direct approach studies.

**Recommendations/implications for practice/ policy**

The need to address childhood obesity (3), and to develop appropriate and effective interventions for overweight and obese people with ID, has already been recognised within international (5, 6) and national policy (7, 8, 9). The present systematic review can help inform clinicians that there is currently insufficient robust evidence to state with confidence that available non-medical childhood obesity interventions are effective when used with CYPID. Clinicians carrying out interventions may be advised to follow best available recommendations intended for typically developing CYP (7, 8), and to make appropriate adaptations (7). International policy (5) recommends that national level policies include and prioritise CYPID, and this has been the case for some countries (7, 8, 9) but not others (17, 18, 19). It is further recommended (5, 6) that national policies include guidance on how such policies are best adapted to suit the needs of CYPID. To date this has not occurred, perhaps due to the lack of existing literature to support such recommendations. The present review, however, provides some initial support for the view that CYPID may benefit from multi-component, systemic approaches, and suggestions may be followed from existing studies which adapted their approach to better suit CYPID (23, 24).
Recommendations/ implications for further research

In order to meet the clinical and policy-driven need to develop appropriate and effective non-medical childhood obesity treatments, more studies are required to evaluate these treatments. Such studies are likely to benefit from an RCT design (20), and a sufficient sample size to allow appropriate statistical analysis. Future research would also benefit from including only overweight and obese participants, and following nationally recommended clinical practice in terms of sufficiently long-term multi-component and systemic interventions and measures (7, 8, 9, 17, 18, 19). As per clinical guidelines (5, 6), adapting interventions to meet the needs of those with disabilities appears effective (23, 24). Reporting attrition and unintended harm would be beneficial.

Further research may also usefully explore any differences in recommended approach between TDCYP and CYPID, which would inform both policy and practice (5, 6). The literature suggests that systemic aspects of treatment (e.g. family and school involvement) may be particularly important for people with ID (30), including supporting informed choices about diet or exercise (31). Important areas to consider for when designing interventions for CYPID are the increased prevalence of challenging behaviour relating to eating (32), fussy eating (33), use of food to relieve loneliness and boredom (27), and as a behavioural reinforcement (32). Some literature suggests that different measures may also be required for CYPID, because their physical health and body composition may differ, particularly if there are mobility difficulties, in which case
typical BMI measures are not useful (34). Therefore, more research may be needed to identify alternatives in areas where typical recommendations do not apply to CYPID.

Future research may additionally address the treatment of those young people transitioning between child and adult services. A large number of excluded studies presently included young adults aged up to 26, and it seems these studies were missed by both this systematic review, and an existing adult (21) systematic review in this area. Further interventions may report cost, in order to support the preventative cost argument of reducing predicted future healthcare costs if obesity goes untreated (3). International policies (5, 6) recommend linking CYPID into existing interventions, in order to reduce costs. It was beyond the scope of the present research to consider effectiveness of interventions for CYPID, taking place amongst mixed ability populations, and this may be an additional area for future research.

Limitations
Conclusions have been drawn based on only a small number of available studies. In the absence of CYPID specific guidelines, the appropriateness of interventions and measures were assessed against guidelines for typically developing children (7, 8), which may not be completely suitable, as discussed above. The present research relies on others’ reports of having recruited populations meeting ID criteria (10) and weight categories. Although different databases may categorise papers under different headings, the selected terms were checked and considered to be sufficiently broad that relevant
papers were not missed as a result of using these identical terms for each database. Use of broad terms may have resulted in increased time taken to sift due to higher numbers of irrelevant papers being found, but increased likelihood of unique papers being found. Finally, the full version of one study could not be retrieved (See Appendix 2).

Key findings
There is limited research to date in this area of clinical and policy driven need. The studies included in the present review were rated as lacking methodological rigour in a number of areas, such as not consistently following recommended clinical approaches, use of non-recommended outcome measures and success criteria, and lack of follow-up measures. Despite these limitations, tentative recommendations can be made for clinicians to use multi-component, systemic approaches with CYPID, and to make adaptations to suit CYPID (23, 24).
References


List of abbreviations and acronyms

BMI: Body Mass Index
CYP: Children and young people
CYPID: Children and young people with an intellectual disability
fem: Female
kg: kilograms
LD: Learning Disability
mal: Male
n/a: not applicable
RCT: Randomised Controlled Trial
SIGN: Scottish Intercollegiate Guidance Network

Graphics: Tables and Figures (and margin size in version to be published)

In copy of article to be submitted, tables and figures will be placed here, rather than throughout text. Margins will be smaller, reducing page numbers significantly.
Chapter 4: Bridging Chapter

The purpose of this brief chapter is to provide a link between the systematic review and the empirical research journal article. In view of the increased prevalence of obesity and overweight amongst CYPLD, and recognition within policies of the need to develop effective interventions to treat this problem, the systematic review has critically explored efficacy of existing interventions. The small number of studies found could have been improved in terms of methodological rigour and adherence to national clinical recommendations (NICE, 2006; SIGN, 2010). However, similar to TDCYP (Waters et al., 2011), a multi-component approach involving diet, and systemic approach involving parents or carers, appears helpful when managing weight with CYPLD. The empirical research journal article will further explore factors predicting parental encouragement of healthy diet amongst CYPID, with a view to informing the development of future interventions. As explained during Chapter 2, the role of parents in the diet of CYPLD may be even more salient than in TDCYP. The theoretical approach being used to underpin this research will be the Theory of Planned Behaviour (TPB; Ajzen, 1991).

The TPB model states that attitude (positive or negative opinion about the behaviour), subjective norm (SN) (perceived views of others approving or disapproving of the behaviour), and perceived behavioural control (PBC) (whether external circumstances will prevent or allow the behaviour), all contribute significantly towards a person’s intention (degree that the person plans to carry out the behaviour). A person is more
likely to perform a specified behaviour if they have a strong intention and minimal perceived external barriers (high PBC) (Ajzen, 1991). This model has been shown to predict parents’ intentions to encourage their child’s healthy eating (Andrews et al., 2010; Astrom et al., 2006), but the model has not yet been applied to parents of CYPLD in relation to encouraging their healthy eating. Researchers have adapted variables included in the model in an attempt to improve its ability to predict intentions and behaviours. Previous research has shown that parents lacking self-efficacy (SE) (the belief of being capable of performing well; Bandura, 1977) in managing their child’s eating-related challenging behaviours, were more likely to have an obese child (West et al., 2009). SE has successfully been added as a predictor variable to the TPB model, improving the ability to predict parents/ carers intentions to encourage a healthy diet amongst TDCYP (Chambers et al., 2007), and amongst adults with a LD (Jenkins et al., 2011). The present study will explore for the first time whether parents’ intentions and behaviours (encouragement of healthy eating by their CYPID) can be significantly predicted by these factors, using the TPB model.
Chapter 5: Extended Methodology

Ethics

Ethical approval

Ethical approval was obtained through University of Edinburgh (Appendix 4), the local NHS ethics committee (providing permission to recruit through NHS clinical teams) (Appendix 5), and Local Authorities (providing permission to recruit through schools) (Appendix 6). Further contact was made with individual voluntary sector organisations and local councils, in order to seek permission to recruit through them (Appendix 7).

Informed consent

Only adults capable of providing informed consent were recruited. Before agreeing to take part, all potential participants were given an opportunity to read a Participant Information Sheet (PIS), and to have any questions answered by either the researcher or by a named independent source. The PIS, which was tailored according to where participants were recruited from, provided information that participation was on a voluntary basis, with the option of stopping involvement at any time. All participants, recruited from any source, were considered to be providing informed consent if they had chosen to go ahead with completing an online questionnaire.
Participant support

The researcher was aware of the possibility that some participants may have given responses indicating they would benefit from dietary advice. As responses were anonymous, it was not possible to provide this. The Participant Information Sheet provided guidance about appropriate sources of additional support, if required. The researcher plans to follow up on all requests from individuals who wished to be informed about findings at the end of the study.

Anonymity and confidentiality

Individual participants were not asked to provide their names, dates of birth, address or other personal details, at any stage. An email address at Time 1 was the only potentially identifiable information obtained by the survey. This email address was used by the researcher to request that a second survey was completed one month later at Time 2 (Appendix 7B). Signed paper consent forms were not used, and so no patient identifiable data existed on paper at any stage. For participants recruited via the NHS, only the direct care team continued to have access to participants’ personal data as per usual clinical practice. In order to link an individual’s Time 1 and Time 2 questionnaires, a unique 4-digit reference number was generated at Time 1, by asking participants for the last two digits from their telephone number, followed by the last two letters of the month they were born. It would not be possible to identify an individual from this information. Email invitations asking all participants to complete the survey at Time 2 were sent using a highly secure NHS staff email account, from an NHS computer. Each email was
deleted immediately from the researcher’s sent items, so that email addresses were not saved, thus destroying any potentially identifying information. Any individual enquiring about the study had their query responded to, before their email address was deleted.

Questionnaire data were collected using password-protected online surveys created using ‘Bristol Online Survey’ (BOS), (Institute for Learning and Research Technology, University of Bristol, 2012). The website for BOS stated that data are stored accurately and securely, and not accessible by the public, thus meeting the requirements of ‘Confidentiality: NHS Code of Practice’ (Division of Health, 2010). Participants were able to access the online survey using their home or other computer, at a convenient time for them. BOS authors corresponded with the researcher, and offered further reassurance that after the online survey ends, data would be stored on their systems for three months only before being destroyed, in keeping with Data Protection legislation. The surveys used in this research did not include any free text questions, and this removed the possibility of respondents providing written answers which might have identified themselves. BOS results were accessed only using a secure NHS computer. Only anonymous data, meaning that the email addresses were no longer included, were transferred from BOS to an Excel spread sheet, for the purpose of data analysis at the University. This transfer of anonymous data from BOS to Excel was made using a secure NHS computer, as recommended by the NHS Confidentiality Policy (NHS Lothian, 2012).
**Participant involvement in research**

Government legislation, such as ‘Valuing People Now’, (Department of Health (DOH), 2009), recommends that health professionals listen and respond to the views of people with a Learning Disability (LD) and their families or carers. With this in mind, the PIS included an invitation to potential participants to provide feedback, this being seen as valuable in identifying ways to improve research processes. Appendix 9: ‘Participant involvement in research design’ demonstrated that every effort was made to take on board and to respond to feedback emailed to the researcher. The researcher planned to disseminate findings to professionals by submitting the article for publication. A summary of findings was passed on to services who assisted with recruitment, and to individuals expressing interest.

**Design, Procedure and Participants**

These detailed sections are provided during the main Empirical Research Journal Article.

**Attempts to reduce attrition**

In order to reduce attrition, meaning that participants might complete the survey at Time 1 but not Time 2, each participant was sent two emails including links to the Time 2 survey.
**Measuring Future behaviour**

The Theory of Planned Behaviour (TPB) is a model which predicts Intention to carry out a behaviour, which in turn predicts behaviour, each based on several expected predicting variables. Due to the difficulty in obtaining data at two points in time, researchers in this field often use past behaviour to replace Future Behaviour within a TPB model (e.g. Jenkins *et al.*, 2011), based on the view that past behaviour predicts future behaviour. This is typically acknowledged by researchers as a limitation in their study design. The present research sought to improve the study design by obtaining measures of behaviour at two points in time (past and future behaviour, taking place one month apart). Using correlations between these variables, and with intention, the present research sought to check the accuracy of this assumption that past, future behaviour and intention are related.

**Recruitment**

*Inclusion and exclusion criteria*

Both versions of the PIS provided potential participants with information about their suitability to take part in the study, under the section, ‘Why have I been asked to take part?’ By including parents of all children on the basis that they had a LD, and by recruiting from a wide range of sources regardless of children’s weight or additional diagnoses, the researcher hoped to recruit a representative sample from the varied LD population (with the exception of those children whose parents were unlikely to be
influential in relation to diet, as explained in the main journal article). Whilst it would have been desirable to include children of all ages, this was beyond the scope of the present research. A decision was made that children required to be aged 5 to 18 years. This was because at the time of planning, the main part of the NHS team, and schools predominantly worked with children over five years of age. The NHS team also reported anecdotally that eating habits often become more established by age five.

*NHS Recruitment*

The NHS team approached was multi-disciplinary and included mainly representatives from psychology, psychiatry, and nursing backgrounds. The clinicians worked with children who have a LD, and with the systems around them (i.e. their schools and families), to address behavioural and emotional problems. The researcher twice attended a meeting held weekly by this NHS team. At the first meeting, the researcher provided verbal and written information about this research to the team. Members of the team were asked to distribute paper copies of the ‘NHS Parent Invitation’ (Appendix 7A) to parents of children on their caseloads. This invitation included a link to an online NHS-version version of the PIS (Appendix 7A). At the second meeting, which took place five months after the first meeting, the researcher provided a verbal reminder, asking for clinicians to continue to recruit up until the survey was planned to close. One email reminder was also sent to clinicians via the team secretary during the recruitment period.
School recruitment

Permission was obtained from two of four local councils approached (Appendices 6A & 6B). The two councils declining were already involved with other projects, and did not wish to place further demands on the parents. One council (Appendix 6A) enabled access to six schools where pupils had a LD, and all six head-teachers were willing to take part. The other council (Appendix 6B) allowed access to four schools where pupils had a LD. Two did not respond, one was unwilling to take part due to other research taking place, and one was willing to take part. Of these seven participating schools, five head-teachers distributed paper copies, and two emailed invitations of the ‘Schools Parents Invitation Letter’ (Appendix 7A) to parents. Follow-up correspondence took place with head-teachers to offer assistance during this process. Some minor variations were made to the wording of the invitation between schools, if this was requested by head-teachers, such as inclusion of the name of the researcher’s academic supervisor. Links to the participant information and surveys remained unchanged.

Voluntary sector recruitment

Some voluntary sector organisations were known to the researcher or supervisors already. Other organisations were identified by searching on the Internet using the term ‘learning disability’. The researcher followed links to further websites from there, including sites aimed at specific syndromes. Seventy-five organisations were identified. Contact was made with an appropriate representative from each organisation by
telephone and/or email (See ‘Voluntary Sector Organisation Email Invitation Seeking Permission to Recruit’ - Appendix 7A). This is an example email, and typically the wording was tailored to the individual organisation. From the 75 organisations approached, 36 showed willingness to support recruitment. Those organisations who did not take part typically did not respond to contact made by the researcher, although two organisations declined to take part because the research was not specifically about their syndrome of interest. Participating organisations usually posted the ‘Voluntary Sector Parent Invitation’ (Appendix 7A) on their website or newsletter, or distributed this invitation in an email to their members (or a combination of these approaches). During the recruitment period, the 36 participating voluntary sector organisations were again contacted and asked whether they could circulate the advert for a second time. Often, the first advert was still available to potential participants, and so re-posting was not necessary. In 14 cases, the advert was posted for a second time. Again, sometimes the wording of the advert was adapted to suit the needs of the individual organisation, for example, shortening to fit a smaller space, but PIS and the surveys remained unchanged.

Ensuring UK definition of LD used

UK websites were used, because this would more likely result in recruitment of individuals using the UK definition of LD. On two occasions however, members from organisations reported posting the invitation on related non-UK websites. In both cases, the researcher insisted that the UK definition of LD be included in the advert (See ‘Non-
UK Voluntary Sector Parent Invitation’ in Appendix 7A), to ensure the correct population was recruited.

**Measures**

*Time 1 survey*

A review of the literature highlighted there was only one available measure of parent self-efficacy relating to managing their child’s weight related behaviours. Although the Lifestyle Behaviour Checklist (LBC: West *et al.*, 2010) was aimed at parents of typically developing children, the items (e.g. eats too much, throws a tantrum about food) appeared equally relevant to children with LD. Following participant feedback (Appendix 9), the PIS was updated to highlight the importance of including children’s non-verbal communications when completing questionnaires. The LBC main author provided permission to use this questionnaire, and personally recommended via email that the researcher use the 2010 rather than 2009 version of LBC (Appendix 8), due to improved wording and improved validity. In order to ensure that parents of children knew they could be included regardless of child weight, and as suggested by the NHS ethics committee, wording of the LBC introductory paragraph was adapted to reflect inclusion of children regardless of weight: ‘Parents with overweight children’, was changed to ‘Parents’.
The Theory of Planned Behaviour Questionnaire (TPB) questionnaire (Chambers et al., 2007) was selected because it was the only known questionnaire aimed at identifying TPB variables, relating specifically to a parent’s intention to encourage healthy eating by their child, which had also been used with people with a LD (Jenkins et al., 2011). The present study used only the TPB part within a larger questionnaire, and with permission from the author (Appendix 8), some minor changes were made to the wording. Whereas previously, parents were asked to rate their intention over the coming year, this was changed to month, to enable comparison with future behaviour captured at Time 2, one month later. An additional question was included, enquiring about the child’s past diet over the past month (Mcgillivray et al. 2013), this being included to better understand characteristics of the population being studied. The past versions of the questionnaire included a reminder of the ‘eat well plate’ healthy eating guidelines, as recommended (Food Standards Agency (FSA), 2007; SIGN, 2010), and this aspect of the questionnaire remained unchanged. Other small changes to wording from earlier versions included that guidelines were positioned ‘above’ rather than ‘on the next page’, and grammatical changes which would not affect meaning.

Some examples of items are shown: The Theory of Planned Behaviour (TPB) states that the outcome variable, intention (‘To what extent do you intend to help your child keep to these guidelines for a healthy diet during the next month?’), has three predictor variables: attitude (e.g. How important to you is controlling your child’s weight?), subjective norm (e.g. ‘Would your child/ partner/ friends disapprove/ approve about
(your child) eating a healthy diet during the next year?’) and perceived behavioural control (e.g. ‘How likely are these factors to stop you from giving your child a healthy diet during the next year?’ Factors include ‘not having enough time…’). Past parent behaviour (e.g. ‘To what extent, over the past year, have you helped your child to keep to the above guidelines?’) and past child diet (‘On average, over the past year, how closely has your child kept to the recommended healthy eating guidelines outlined above?’) were included. There were nine items in total, some consisting of only one question, and others consisting of up to nine further questions. Responses could be made using seven-point Likert scales, with some questions having an eighth ‘not applicable’ option. perceived behavioural control items had scores reversed, and otherwise the system for scoring has been described in the main article.

In addition to the main LBC and TPB questionnaires, socio-demographic questions were included, as described in the main article. Jenkins et al. (2011) reported that their research could be improved by including a measure of obesity levels. Information from which parent and child BMI could be calculated was included in the present research, so as to find how this population compares with the typical UK population. Parents were asked to generate their unique 4 digit identifying code to link Time 1 and 2 responses, these being non-identifying.
**Time 2 survey**

This shorter survey aimed to measure behaviour (parental encouragement of their child to eat a healthy diet) one month after the Time 1 survey. A literature review demonstrated a lack of available questionnaires to measure this construct, and so Chambers’ TPB intention question, having validity and reliability in its original version, was adapted to assess parents’ future behaviour (‘To what extent, over the past month, have you helped your child to keep to the above guidelines?’) and child future diet (‘On average, over the past month, how closely has your child kept to the recommended guidelines for healthy eating outlined above?’). Both referred to the recommended ‘eatwell plate’ (SIGN, 2010). Many alternative measures were available to measure child future diet, such as the Food Frequency Questionnaire (FFQ), (McGuire *et al.*, 2007). Child diet was not central to the TPB model, and so this simple single-tem measure was preferred, not least because this was hoped to reduce attrition by being easier for participants than completing an additional lengthy questionnaire or engaging with time-consuming observation of meals. Both of these future behaviour and future child diet questions had the benefit of being already worded in a style suited to parents about their children, and both were comparable with other data collected within this research.

**Statistical analysis and decision to use SEM**

These have been described in the main article, and so will not be repeated presently.
Chapter 6: Empirical Research Journal Article

(See Appendix 3 for Author Guidelines: Journal of Applied Research in Intellectual Disabilities (JARI))

Cover page containing title only:

Parents’ intentions to provide a healthy diet for children with an intellectual disability: The application of a revised Theory of Planned Behaviour
(In the version to be submitted for publication, author names and contact details will be added to this page, and tables will be presented at the end of the article, with figures provided in a separate document).

Running title: Parental role in diet of children who have an ID

Keywords: Theory of Planned Behaviour (TPB)

Intellectual Disability (ID)

Parent

Child

Diet

Self-efficacy

Word count = 5753 words (Journal allows 2-7000 excludes titles, references and tables but not abstracts)
Abstract

**Background:** Children and Young People who have an Intellectual Disability (CYPID) have a higher prevalence of obesity and overweight than typically developing children and young people (TDCYP), and research is needed to inform appropriate interventions. The present study explored whether the Theory of Planned Behaviour (TPB), and an expanded model including self-efficacy (SE), significantly predicted parental intention and behaviour, in encouraging healthy eating by CYPID.

**Materials and Methods:** Parents (N=190) completed two online questionnaires one month apart, providing data relevant to both TPB models. Structural equation modelling and correlations were used to analyse the data.

**Results:** Data fitted well for both versions of the TPB model (based on CFI and RMSEA indices), and the original model (having the lower of the two BIC indices) was a better fit than the extended model. Significant predictors of intention were not identified by either model.

**Conclusions:** SEM demonstrated the suitability of both TPB models, but particularly the original model, for informing practice in relation to parents’ intentions and encouragement of healthy eating by CYPID. Interventions targeting parent’s attention, subjective norm, perceived behavioural control, and self-efficacy, are unlikely to be
effective in improving parental encouragement of child healthy eating, for CYPID. Developers of future interventions should consider that this population has more special diets, mobility difficulties, and areas of clinical need: child over- and under-weight, parent over-weight, child weight-related challenging behaviour, and parent’s low self-efficacy in managing these. Further research could develop improved population appropriate measures, as well as identify variables that predict parent’s encouragement of CYPID healthy eating.
Introduction

Clinical and policy driven rationale for researching topic

Globally, childhood overweight and obesity are increasing in prevalence (World Health Organisation (WHO) 2011), including for those with an intellectual disability (ID) (Marshall et al. 2003). Children and young people with an ID (CYPID) have a higher incidence of obesity compared to Typically Developing Children and Young People (TDCYP). For example, 36% CYPID in Scotland are obese (Stewart et al. 2009) compared to 14% of TDCYP (Scottish Government 2011); 22% of CYPID in United States have a Body Mass Index (BMI) percentile above 95%, compared with 15.7% of TDCYP (Bandini et al. 2005); 26% of French CYPID in France are overweight or obese (Salaun et al. 2010) compared to 14% of TDCYP (International Obesity Taskforce (IOTF) 2011); 40% of CYPID in Australia (De et al. 2008) are overweight or obese compared to 23% of TDCYP (IOTF 2011)). In addition, more CYPID are underweight (37%; Marshall et al. 2003), compared to 2.6% in the general child population (e.g. Scottish Government 2011), this also increasing their risk of earlier mortality (WHO 2011). Obesity negatively impacts on physical and emotional health, and reduces life span (WHO 2011). Deviations from a healthy weight further contribute to already unmet health needs for people with an ID (Hamilton et al. 2007; National Health Service (NHS) Health Scotland 2004). In Scotland, a government ‘Heat 3’ target has been set to manage this problem by providing more weight interventions (Scottish Government 2012). Internationally (WHO 2010; WHO 2012), and nationally (National Health and
Medical Research Council (NMHRC) 2013; National Institute for Health and Clinical Excellence (NICE) 2006, Scottish Intercollegiate Guidelines Network (SIGN) 2010), there is policy recognition of the need to address weight in CYPID, and to carry out research to inform the development of ID appropriate weight management interventions.

A systematic review on treating childhood obesity (Waters et al. 2011) highlighted that, whilst recommended treatment components (diet, exercise, reducing sedentary behaviours, inclusion of parents and schools; NICE 2006; NMHRC 2013; SIGN 2010) are typically effective when combined, future research should aim to identify specific effective components. The importance of addressing diet was highlighted as one of four areas to target in the plight to reduce disease and death resulting from non-communicable diseases (WHO 2013). CYPID may rely more heavily on parents to provide healthy dietary choices (Fox et al. 1985; Hamilton et al. 2007), including to support informed choices in considering the long-term consequences of diet (Marshall et al. 2003; Smyth et al. 2006). Another systematic review demonstrated the importance of parental perceptions, attitudes and behaviours in influencing diet in CYPID (Mcgillivray et al. 2013). The present study intends to specifically explore the parent’s role in encouraging the child’s healthy diet, which is hoped to inform the development of future weight management interventions for CYPID.
**Theoretical rationale**

The Theory of Planned Behaviour (TPB) model (Ajzen 1991) was selected as an appropriate theoretical approach to underpin the present research, because it has been successfully applied to identify predictive factors for a range of health behaviours, including diet (Armitage et al. 2001). The TPB states that attitude (positive or negative opinion about the behaviour), Subjective Norm (SN) (perceived views of others approving or disapproving of the behaviour), and Perceived Behavioural Control (PBC) (whether external circumstances will prevent or allow the behaviour), all contribute significantly towards a person’s Intention (degree that person plans to carry out the behaviour). A person is more likely to perform a specified behaviour if they have a strong intention and minimal perceived external barriers (high PBC) (Ajzen 1991). This original TPB model (Fig.1) has been found to predict 31-94% of the variance in child (Bazillier et al. 2011; Hewitt et al. 2007) and adolescent (Berg et al. 2000; Lien et al. 2002) healthy eating intentions and behaviours, and it has successfully been applied to predict parents’ intentions to encourage children aged under 5 years to eat a healthy diet (Astrom et al. 2006; Andrews et al. 2010). The present study will explore for the first time whether parents’ intentions and behaviours (encouragement of healthy eating by their CYPID) can be significantly predicted by the TPB model. Dietary researchers in this field often use past behaviour in place of future behaviour within a TPB model (as summarised by Armitage et al. 1999) based on the views that past behaviour predicts future behaviour (Ajzen 1991). Researchers typically acknowledge as a study design limitation when they have not checked intention against actual behaviour (e.g. Jenkins et
Future behaviour is expected to have a stronger correlation than past behaviour with intention (Armitage et al. 1999). The present research included measures of behaviour at two points in time (past and future behaviour, taking place one month apart) so as to explore this further.

Previous research has shown that parents lacking self-efficacy (SE) (the belief of being capable of performing well; Bandura 1977) in managing their child’s eating-related challenging behaviours, were more likely to have an obese child (West et al. 2009). Whilst Ajzen (1991) originally perceived SE and PBC as one and the same, factor analyses have since shown them to be separate concepts (e.g. Armitage et al. 1999; Norman et al. 2004). Armitage et al. (1999) defined PBC as an individual’s perception about external control factors, whereas SE is about internal control factors such as motivation. The addition of SE to the TPB model, which already includes PBC (external focus), has been successful in predicting adult (Povey et al. 2000; Armitage et al. 1999), and child (Fila et al. 2006) intentions to eat healthily, and parents’ intentions to support healthy eating by their child (Chambers et al. 2007); with SE being the strongest predictor in some studies (Armitage et al. 1999; Chambers et al. 2007). The addition of SE and another variable to the original TPB model resulted in a 4% improvement in the model’s ability to predict carers’ intentions to encourage adults with an ID to eat healthy food (Jenkins et al. 2011). A direct effect of SE on dietary behaviour has been demonstrated in some research (e.g. Fila et al. 2006), but not others (e.g. Armitage et al. 1999). This expanded TPB model, with or without a direct relationship between SE and
behaviour, has not yet been applied to predict parents’ encouragement of healthy eating by CYPID.

![Diagram of the Original Theory of Planned Behaviour (TPB) Model (Ajzen 1991), with additional Self-efficacy (SE) variable being added (shown by dotted lines) to create an Extended Theory of Planned Behaviour Model (SN= Subjective Norm; PBC = Perceived Behavioural Control)]

**Aims and hypotheses**

The present study firstly aimed to test whether the original TPB model (Fig. 1) significantly predicts intention and behaviours of parents or carers to encourage a healthy diet in CYPID. Secondly, it aimed to explore whether the addition of parental self-efficacy in managing their child’s weight-related behaviours (including unhealthy diet), improves the model’s predictive ability. It was hypothesised that: Intention of parents to encourage children with an ID to eat healthily will be predicted by attitude, SN and PBC; behaviour will be predicted by Intention and PBC; the predictive ability of the model will be improved by the addition of SE as a predictor of both intention and
behaviour. Past and future behaviour and intention were expected to all correlate positively and significantly.

**Methods and Materials**

Ethical approval was obtained through University of Edinburgh (Appendix 4), the local NHS ethics committee (providing permission to recruit through NHS clinical teams) (Appendix 5) and Local Authorities (providing permission to recruit through schools) (Appendix 6). The research design was a survey with two time points. Questionnaire data were collected using password-protected online surveys created on ‘Bristol Online Survey’ (BOS; Institute for Learning and Research Technology, University of Bristol 2012). Having had an opportunity to read an information sheet about the survey, participants were considered to be providing consent if they had chosen to go ahead with completing an online questionnaire at T1. One month later, T1 completers were emailed a link to a follow-up (T2) questionnaire (Appendices 7-8). Participants took part on a voluntary basis; they were free to withdraw and advised their responses would be anonymous. Each survey remained accessible for six and a half months.

**Participants and Sample size**

Only those attempting both main sections of the Time 1 questionnaire were included, this reducing participant numbers from 214 to 190 at Time 1. Email details were provided by 163 of the Time 1 participants, enabling 104 to respond to requests to complete the survey at Time 2. Only 80 of the Time 2 participants could be included
due to 4-digit codes enabling matching with their Time 1 responses (due to being present, correctly matching, and not identical to any other participant’s code). As per Table 1, the sources of recruitment for the 190 Time 1 participants were NHS (5), schools (7), voluntary sector (151), and source unknown due to incomplete data (28). Amongst the 190 participants included at Time 1, there were 8 men and 163 women (N= 19 gender not reported). The ages of participants ranged from 24 to 58, with a mean age of 42 (standard deviation (SD) = 7.8), (N= 20 age not reported). Ages of each participant’s child being referred to in this research ranged from 5 to 18 years, with a mean age of 10 (SD = 4.0) (N= 19 age not reported), (107 boys, 64 girls, (N=19 gender not reported).

Bentler et al. (1987) recommend that 10 or 5 participants are required for every estimated parameter when using Structural Equation Modelling (SEM), and they recommend no more than 20 variables. Based on the 14 parameters from the Fig. 1 model (7 shown arrows and 7 error arrows not shown), the minimum required sample size was 70 (Bentler et al. 1987). Therefore, the present 190 participants, and subset of 80 at Time 2 (T2), provided a sufficient sample size. This minimum sample size was ethically approved during Time 1 recruitment (Appendix 5E). Approval of this amendment allowed SEM to be used, this being superior to the former path analyses method (Coffman et al. 2005), and achievable given successful recruitment.
Table 1. Socio-demographic descriptive statistics: Parent & Child Gender, Child Dietary requirements, Recruitment source, Child mobility, Parent & Child BMI, Parent & Child Age) for participants completing survey at Times 1 (T1) and the subset who completed the survey at Time 2 (T2).

<table>
<thead>
<tr>
<th>T1 completers (N=190)</th>
<th>N (%)</th>
<th>T2 completers (N=80 subset)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent Gender:</strong></td>
<td></td>
<td><strong>Parent Gender:</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8 (4.2%)</td>
<td>Male</td>
<td>3 (3.8%)</td>
</tr>
<tr>
<td>Female</td>
<td>163 (85.8%)</td>
<td>Female</td>
<td>77 (96.3%)</td>
</tr>
<tr>
<td>MD</td>
<td>19 (10%)</td>
<td>MD</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Child Gender:</strong></td>
<td></td>
<td><strong>Child Gender:</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>107 (56.3%)</td>
<td>Male</td>
<td>48 (60%)</td>
</tr>
<tr>
<td>Female</td>
<td>64 (33.7%)</td>
<td>Female</td>
<td>32 (40%)</td>
</tr>
<tr>
<td>MD</td>
<td>19 (10%)</td>
<td>MD</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Child any dietary requirements:</strong></td>
<td></td>
<td><strong>Child any dietary requirements:</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>121 (63.7%)</td>
<td>No</td>
<td>57 (71.3%)</td>
</tr>
<tr>
<td>Yes</td>
<td>50 (26.3%)</td>
<td>Yes</td>
<td>23 (28.7%)</td>
</tr>
<tr>
<td>MD</td>
<td>19 (10%)</td>
<td>MD</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Recruitment source:</strong></td>
<td></td>
<td><strong>Recruitment source:</strong></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>7 (3.7%)</td>
<td>School</td>
<td>3 (3.8%)</td>
</tr>
<tr>
<td>NHS</td>
<td>5 (2.6%)</td>
<td>NHS</td>
<td>2 (2.5%)</td>
</tr>
<tr>
<td>Voluntary sector</td>
<td>151 (79.5%)</td>
<td>Voluntary sector</td>
<td>75 (93.8%)</td>
</tr>
<tr>
<td>MD</td>
<td>27 (14.2%)</td>
<td>MD</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Child ability to move freely:</strong></td>
<td></td>
<td><strong>Child ability to move freely:</strong></td>
<td></td>
</tr>
<tr>
<td>Very able</td>
<td>105 (55.3%)</td>
<td>Very able</td>
<td>43 (53.8%)</td>
</tr>
<tr>
<td>Fairly able</td>
<td>56 (29.5%)</td>
<td>Fairly able</td>
<td>28 (35.0%)</td>
</tr>
<tr>
<td>Not able</td>
<td>10 (5.3%)</td>
<td>Not able</td>
<td>9 (11.3%)</td>
</tr>
<tr>
<td>MD</td>
<td>19 (10%)</td>
<td>MD</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Parent BMI:</strong></td>
<td></td>
<td><strong>Parent BMI:</strong></td>
<td></td>
</tr>
<tr>
<td>Underweight (0% after missing data excluded)</td>
<td>0 (0%)</td>
<td>Underweight</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Normal (39% after missing data excluded)</td>
<td>60 (31.6%)</td>
<td>Normal</td>
<td>30 (37.5%)</td>
</tr>
<tr>
<td>Overweight (40% after missing data excluded)</td>
<td>62 (32.6%)</td>
<td>Overweight</td>
<td>31 (38.8%)</td>
</tr>
<tr>
<td>Obese (21% after missing data excluded)</td>
<td>33 (17.4%)</td>
<td>Obese</td>
<td>16 (20.0%)</td>
</tr>
<tr>
<td>MD</td>
<td>35 (18.4%)</td>
<td>MD</td>
<td>3 (3.8%)</td>
</tr>
<tr>
<td><strong>Child BMI:</strong></td>
<td></td>
<td><strong>Child BMI:</strong></td>
<td></td>
</tr>
<tr>
<td>Underweight (12% after missing data excluded)</td>
<td>16 (8.4%)</td>
<td>Underweight</td>
<td>11 (13.8%)</td>
</tr>
<tr>
<td>Normal (47% after missing data excluded)</td>
<td>61 (32.1%)</td>
<td>Normal</td>
<td>30 (37.5%)</td>
</tr>
<tr>
<td>Overweight (10% after missing data excluded)</td>
<td>13 (6.8%)</td>
<td>Overweight</td>
<td>9 (11.3%)</td>
</tr>
<tr>
<td>Obese (30% after missing data excluded)</td>
<td>39 (20.5%)</td>
<td>Obese</td>
<td>14 (17.5%)</td>
</tr>
<tr>
<td>MD</td>
<td>61 (32.1%)</td>
<td>MD</td>
<td>16 (20.0%)</td>
</tr>
<tr>
<td><strong>Parent Age:</strong></td>
<td></td>
<td><strong>Parent Age:</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>41.6 (7.8)</td>
<td>Mean (SD)</td>
<td>41.9 (7.9)</td>
</tr>
<tr>
<td>Range</td>
<td>24 to 58</td>
<td>Range</td>
<td>24 to 57</td>
</tr>
<tr>
<td>MD: N (%)</td>
<td>20 (10.5%)</td>
<td>MD: N (%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Child Age:</strong></td>
<td></td>
<td><strong>Child Age:</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>10.4 (4.0)</td>
<td>Mean (SD)</td>
<td>10.2 (4.0)</td>
</tr>
<tr>
<td>Range</td>
<td>5 to 18</td>
<td>Range</td>
<td>5 to 18</td>
</tr>
<tr>
<td>MD: N (%)</td>
<td>19 (10%)</td>
<td>MD: N (%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

N = Number of participants; SD= Standard Deviation; T1 = Time 1; T2 = Time 2; MD = Missing data; NS = Not significant
**Time 1 survey**

At time 1, participants were asked to complete the measures related to self-efficacy, constructs from the TPB and to provide socio-demographic information.

*Lifestyle Behaviour Checklist (LBC; West & Sanders 2009).*

This 25-item survey of parents’ confidence in managing children’s weight-related behaviours (e.g. “throws a tantrum about food”) was described by the authors as measuring ‘lifestyle-specific parenting self-efficacy’. Although scored the other way round according to the literature (West et al. 2009; West et al. 2010), the recommended version of the questionnaire was received directly from the authors (See Appendix 8), in which items were scored on a 10-point Likert scale where 1 = certain I can’t do it, and 10 = certain I can do it, and so higher scores indicate greater levels of confidence. This tool additionally measures child behaviour relating to weight and eating, on a 7-point Likert scale, with higher scores indicating more problematic behaviour. SE and Child Behaviour scores were created by summing totals for either variable, and each variable had a clinically relevant cut-off point, determined by the authors. Whereas both Child Behaviour and SE total scores were used in correlations, only the parent’s SE was used in SEM. 4 subscale scores were created for use in SEM by summing items known to load onto each of four factors (West et al. 2010). The four factors approximately represented feeding behaviours, excessive eating (not necessarily relating to healthiness of foods), exercise, and impact of weight. Both Child Behaviour and parent’s SE scales had good construct validity, correlating significantly with existing parenting and child
behaviour scales (West et al. 2009; West et al. 2010). The authors reported good internal consistency, with Cronbach’s alpha scores all above .90. In the present study, SE (α = .96) and Child Behaviour (α = .90) also had good internal reliabilities (as indicated by scores of over 0.70: Nunally 1978). Wording of the introductory paragraph was adapted to reflect participant inclusion regardless of weight.

*TPB-adapted measure (Chambers et al. 2007).*

This measure was chosen because it has been used previously in relation to predicting parents’ encouragement of their child’s healthy diet (Chambers et al. 2007), using relevant factors (attitude, PBC, SN, intention, behaviour), and because the items refer to the recommended ‘eat well plate’ guidelines (SIGN 2010). Wording was adapted to reflect intention over the coming month rather than year so as this was comparable with behaviour data collected one month later. A measure of children’s eating was included as recommended (Mcgillivray et al. 2013), based on TPB parent behaviour questions, and using a similar Likert scale: ‘On average, over the past year, how closely has your child kept to the recommended healthy eating guidelines outlined above?’ (1 = not closely at all, 7 = very closely). Other variables (attitude, PBC and SN) used multiple questions with a variety of seven-point Likert scales (e.g. 1 = very unlikely, 7 = very likely; 1 = disapprove, 7 = approve). PBC items referred predominantly (89%) to external control factors, such as cost and convenience. SN items included an eighth ‘not applicable’ option. Chambers (2009) carried out a factor analysis demonstrating good construct validity of TPB variables, and good internal reliabilities (Nunally 1978): SN (α
=.75), attitude (α =.96), and PBC (α =.90). In the present research, PBC (α = .83) and attitude (α = .90) had good reliability. A single SN item was removed, relating to child approval about healthy eating over the next year, this change resulting in improved, but still not acceptable internal reliability (Before: α = .41; After: α = .61). The removed item appeared unsuitable with this population, because CYPID may have difficulty understanding long-term health consequences of diet (Marshall et al. 2003; Smyth et al. 2006). The author’s scoring guidelines recommend multiplying pairs of scores (belief x outcome evaluation), then summing these to form a total score for each multiple-item variable. Whilst total scores were used for correlations, pairs of scores created using author’s guidelines were ‘parcelled’ for SEM analyses (See ‘Quality of data’).

Socio-demographic information

To provide a context about some of the additional challenges present, parents were asked whether their child had any specific dietary requirements (yes/ no) and how mobile the child is (very/ fairly/ not very able to move freely). Questions included parent and child’s age, gender, height and weight, source of recruitment, and email address (the latter for invitation to participate at T2). Body mass indices (BMI) were calculated for parents and children, taking into account children’s age and gender (DOH 2012), based on internationally recommended standards (WHO 2006).
Time 2 Survey

At time 2, Chamber’s et al. (2007) intention question was adapted to form two new questions: ‘Over the past month, how closely has your child kept to the recommended guidelines for healthy eating?’ (child future diet) and ‘To what extent, over the past month, have you helped your child to keep to the above guidelines?’ (behaviour). Both were rated on a single item 7-point Likert scale (e.g. 1 = not at all, 7 = completely).

Inclusion and exclusion criteria

Participants were parents of a child with an ID, aged 5 to 18 years. Participants were assumed to exert an influence over diet, and therefore living with their child was essential. Parents whose child required a carefully controlled diet (e.g. tube-fed; diagnosis of Prader-Willi Syndrome) were excluded.

Recruitment

Parents of children with an ID were recruited from a Learning Disabilities (LD) team within the NHS, seven special schools, and 36 Voluntary Sector Organisations. Table 1 showed socio-demographic descriptive statistics for the 190 participants completing the survey at Time 1 (T1 completers), and a subset of 80 participants (42%) completing a Time 2 (T2 completers) survey. No significant differences were found between T1 completers and T2 completers on socio-demographic variables.
Statistical analyses

Data were analysed using correlations on SPSS (IBM 2010), and Structural Equation Modelling (SEM) on Mplus Version 6 (Muthen et al. 2010). SEM typically enables hypothesis testing including direction of causality, improved accuracy due to including measurement error, and allowing latent variables to be used in analysis (Byrne 2012).

Quality of data

There were no significant differences in gender, dietary requirements, recruitment source, child mobility, parent and child BMI, and parent age, between T1 and T2 completers (Table 1). With the exception of SE, T1 and T2 completers demonstrated no difference in scores on any ‘main’ variables to be used in SEM analysis, including intention, SN, PBC, or behaviour (Table 2). T2 completers had greater SE (U = 3522.0; z = -0.34; p<0.01), and less clinically significant SE scores (X2(3) = 12.4; p<0.01).

There were no missing data on ‘main’ variables obtained at T1. However, SN items included a ‘not applicable’ option, (intended for use when a partner or friends may not be present or a child may be unable to express their views), resulting in 39.4% of missing SN data. SN total scores were treated as missing for any participant who did not complete all included items. SN data were missing completely at random (MCAR), this being demonstrated using Little’s Test in SPSS (Little 1988). Codes for missing SN and future behaviour data were entered onto Mplus, so that these could be taken into account during analyses (Muthen et al. 2010). Separate SEM analyses were carried out using both past and future behaviour (e.g. Ajzen 1991), due to 58.4% of the original sample
not completing the survey at Time 2. Data were normally distributed for attitude and future behaviour only, i.e. intention, SN, PBC, SE and past behaviour scores were not normally distributed. Data can be parcelled as an alternative to transforming or estimating data when non-normally distributed variables are present, which increases reliability; use of latent variables in this way during SEM is preferable to using mean scores with path analyses (Coffman et al. 2005). Multiple-item TPB variables were parcelled using pairs of scores according to the author’s guidelines, and groups of 3 pairs were summed rather than creating single total scores. SE was conceptually parcelled (Coffman et al. 2005), by summing items known to load onto each of four factors (West et al. 2010). In addition to parcelling, SEM analyses were performed using the typically used ML estimator, followed by the recommended (Muthen et al. 2013) ‘MLR’ estimator (a maximum likelihood estimation which is robust despite non-normality and missing data).

**Results**

**Correlation matrix**

Due to the number of variables which were not normally distributed, non-parametric Spearman’s correlations were carried out (Table 3). Original data were used rather than transformed data with more sensitive Pearson’s correlations, because non-transformed outcomes are more readily understood, and because SEM does not require data to be normally distributed (Muthen et al. 2013). The T1 completers’ data were used for all
correlations and SEM due to this being a larger data set. T2 completer’s data were additionally presented for SE correlations, because the two data sets had significantly different SE scores. Regardless whether T1 or T2 data were used, correlations demonstrated relationships between variables as would be expected using the original TPB model, with the exception that SN and intention were positively but not significantly related (Ajzen 1991). Attitude and PBC with intention, and intention with behaviour were most significant (p<0.01). Using the T1 data set only, predictive variables were unrelated to one another, as the model predicts. PBC and SE were low in their correlations with one another, supporting the view these are conceptually different from one another.
Table 2. Descriptive statistics for ‘Main’ TPB and LBC variables, for Time 1 (T1) completers and Time 2 (T2) completers.

<table>
<thead>
<tr>
<th>Variable (from TPB or LBC survey)</th>
<th>Time 1 completers (N=190)</th>
<th>% missing</th>
<th>Time 2 completers subset (N=80)</th>
<th>% missing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD) &amp; Range</td>
<td></td>
<td>Mean (SD) &amp; Range</td>
<td></td>
</tr>
<tr>
<td>1. Intention (TPB)</td>
<td>5.8 (1.2)</td>
<td>None N=190</td>
<td>5.8 (1.2)</td>
<td>None</td>
</tr>
<tr>
<td>2. Attitude (TPB)</td>
<td>336.4 (107.5)</td>
<td>None N=190</td>
<td>323.4 (103.9)</td>
<td>None</td>
</tr>
<tr>
<td>3. SN (TPB)</td>
<td>43.1 (26.4)</td>
<td>N=115 39.4%</td>
<td>44.52 (25.8)</td>
<td>N=50 (37.5%)</td>
</tr>
<tr>
<td>4. PBC (TPB)</td>
<td>298.0 (96.5)</td>
<td>None N=190</td>
<td>298.3 (87.4)</td>
<td>None</td>
</tr>
<tr>
<td>5. SE (LBC)</td>
<td>185.0 (50.2)</td>
<td>None N=190</td>
<td>196.3 (46.3)</td>
<td>None</td>
</tr>
<tr>
<td>6. Past behaviour (Time 1, TPB)</td>
<td>5.4 (1.4)</td>
<td>None N=190</td>
<td>5.4 (1.5)</td>
<td>None</td>
</tr>
<tr>
<td>7. Future behaviour (Time 2, TPB)</td>
<td>5.1 (1.3)</td>
<td>N=79 58.4%</td>
<td>5.1 (1.3)</td>
<td>N=79 (1.3%)</td>
</tr>
<tr>
<td>8. Child past diet (Time 1, TPB)</td>
<td>4.2 (1.9)</td>
<td>None N=190</td>
<td>4.1 (2.0)</td>
<td>None</td>
</tr>
<tr>
<td>9. Child future diet (Time 2, TPB)</td>
<td>4.1 (1.6)</td>
<td>42% N=80</td>
<td>4.2 (1.6)</td>
<td>None missing, N=80</td>
</tr>
<tr>
<td>10. Child behaviour (LBC)</td>
<td>71.9 (27.4)</td>
<td>None N=190</td>
<td>69.1 (26.0)</td>
<td>None</td>
</tr>
</tbody>
</table>

**TPB = Theory of Planned Behaviour survey; LBC = Lifestyle Behaviour Checklist survey; NS = Not Significant; SN = subjective norm; PBC = Perceived behavioural control; SE = Self Efficacy.**

Criteria were met for all main variables to be ‘continuous’, and to demonstrate homogeneity of variance using Levene’s test (Field, 2009). However, the third requirement for parametric data, normal distribution, (demonstrated by calculations of skewness divided by skewness standard error) (Field, 2009), was met for all except intention, SN, PBC, SE, and past parent behaviour. Therefore a mix of parametric independent t-tests, and non-parametric Mann Mann-Whitney tests were performed.

**Correlation is significant at the 0.01 (1-tailed) level.**

*Correlation is significant at the 0.05 (1-tailed) level.*
Table 3. Correlation matrix showing relationships between each pair of variables, using Spearman’s correlation coefficients

<table>
<thead>
<tr>
<th>Variable (TPB or LBC survey)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intention</td>
<td>1</td>
<td>.37 **</td>
<td>.11 NS</td>
<td>.21 **</td>
<td>.28 *</td>
<td>.69 **</td>
<td>.33 *</td>
<td>.40 **</td>
<td>.30 *</td>
<td>.10 NS</td>
</tr>
<tr>
<td>2. Attitude</td>
<td></td>
<td>-0.03 NS</td>
<td>.06 NS</td>
<td>.10 NS</td>
<td>.014 NS</td>
<td>.26 NS</td>
<td>.23 NS</td>
<td>.25 NS</td>
<td>.33 *</td>
<td>.08 NS</td>
</tr>
<tr>
<td>3. SN</td>
<td>1</td>
<td>-0.13 NS</td>
<td>-0.22 NS</td>
<td>-3.57 **</td>
<td>.21 NS</td>
<td>.02 NS</td>
<td>.29 NS</td>
<td>.13 NS</td>
<td>-0.01 NS</td>
<td></td>
</tr>
<tr>
<td>4. PBC</td>
<td>1</td>
<td>.23 NS</td>
<td>-2.57 *</td>
<td>.35 *</td>
<td>.40 **</td>
<td>.38 **</td>
<td>.37 **</td>
<td>-0.16 NS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. SE</td>
<td>1</td>
<td>-.12 NS</td>
<td>-0.75 NS</td>
<td>.03 NS</td>
<td>.046 NS</td>
<td>.19 NS</td>
<td>.192 NS</td>
<td>.13 NS</td>
<td>-.61 **</td>
<td>-.486 **</td>
</tr>
<tr>
<td>6. Past behaviour (T1)</td>
<td>1</td>
<td>.62 **</td>
<td>.63 **</td>
<td>.51 **</td>
<td>.03 NS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Future behaviour (T2)</td>
<td>1</td>
<td>.46 **</td>
<td>.71 **</td>
<td>.02 NS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Child past diet (T1)</td>
<td>1</td>
<td>.62 **</td>
<td>.20 NS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Child future diet (T2)</td>
<td>1</td>
<td>-.15 NS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Child behaviour</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

T = Time. NS = Not Significant. SN = Subjective norm. PBC = Perceived Behavioural Control. SE = Self efficacy. Time 2 correlations shown in italics.

** = Correlation is significant at the 0.01 level (1 tailed)
* = Correlation is significant at the 0.05 level (1 tailed)
Figure 2: Structural regression path for TPB Original Model (Best fitting model according to SEM), showing individual residual variances and significance of each, using Time 1 (T1) completer data. SN = Subjective Norm; PBC = Perceived Behavioural Control; SE = Self-efficacy. Behaviour = (parent) Past Behaviour. NS = Not significant. ** = significant (P<0.001)

Figure 3: Structural regression path for TPB Extended Model (SE & Behaviour being linked), showing individual residual variances and significance of each, using Time 1 (T1) completer data. SN = Subjective Norm; PBC = Perceived Behavioural Control; SE = Self-efficacy. Behaviour = (parent) Past Behaviour. NS = Not significant. ** = significant (P<0.001)
Both data sets showed SE and both past and future behaviour to be unrelated. Past behaviour was most strongly related with both intention and with future behaviour (p<0.01), whereas future behaviour and intention were less significantly related, judging from the size of correlations (p<0.05). Parent behaviours and child past and future diet were all strongly correlated with one another (p<0.01).

**Testing the measurement model (Confirmatory Factor Analysis)**

Confirmatory Factor Analysis (CFA) involves examining underlying constructs of the measurement model. The measurement model refers to how well each of the latent variables is represented by the set of items being used to measure them (Byrne 2012). Individual CFA’s for each variable showed all items loaded sufficiently on their expected variable, demonstrating suitability for inclusion in full model CFA’s (Byrne 2012). ML and MLR estimators both consistently produced identical results, and so the ML estimator was used, to increase ease of comparing models. Best fitting CFA’s for original (χ²(24) = 0.35, p<0.35, CFI = 0.99, RMSEA = 0.03) and extended (χ²(59) = 81.64, p = 0.03, CFI = 0.96, RMSEA = 0.07) TPB models were achieved with listwise marked ‘on’ (a setting which excludes all data for participants where any data being analysed are missing), past rather than future behaviour, and SE directly predicting behaviour in the extended model. Good fits on both models were indicated according to >0.95 for incremental (CFI) (Hu et al. 1999) and <.08 absolute (Root mean square error of approximation: RMSEA) (Browne et al. 1993) fit indices. These good fits indicated
that measured items represented latent variables using the sample data, and therefore continuing with SEM appeared meaningful and appropriate (Byrne 2012).

**Structural model (Structural Equation Modelling (SEM))**

The structural model (using SEM) additionally includes causal pathways (Byrne 2012). The original and extended TPB models were not nested, due to the inclusion of SE in the extended model only, and so model comparison using BIC (in which the model having lowest BIC has the better fit) was appropriate (Byrne 2012). Similar to during CFA’s, best fitting SEM’s have been reported based on Time 1 data, using Past behaviour, listwise marked ‘on’, and SE predicting both intention and behaviour. SEM demonstrated that the original ($\chi^2(38) = 46.13$, $p = 0.17$, CFI = 0.98, RMSEA = 0.05, BIC = 8226.27) was a better fit than the extended ($\chi^2(79) = 107.17$, $p = 0.02$, CFI = 0.96, RMSEA = 0.06, BIC = 11065.83) model. Both models demonstrated non-significant pathways between all predictor variables and intention, and only intention was a significant predictor of Behaviour ($p < 0.001$) (Fig. 2 & Fig. 3 shows structural regression pathways for the best fitting original & extended SEM models).

**Discussion**

**Original model**

The present study supported the hypothesis that the original TPB was a good fit (based on CFI and RMSEA fit indices) when used to explore parental encouragement of healthy
eating by their CYPID. Past literature demonstrates suitability of this model with parents of TDCYP only (Astrom et al. 2006; Andrews et al. 2010). The SEM structural regression pathways demonstrated that intention to behaviour was the only significantly predicting parameter within the model, which may be indicative that factors not included in the model may also contribute towards intention. A TPB meta-analysis suggested that a strong relationship between intention and behaviour (as in the present research), indicates that intenders have good volitional control to exert the behaviour (Armitage et al. 2001).

Extended model

The present research hypothesised that the addition of SE in the extended model would improve the model fit (based on a comparison of BIC fit indices between the original and extended models). This hypothesis was not supported, suggesting that the original was the better of the two models. In other words, parents’ intention and behaviour managing their child’s weight related behaviours including to eat more healthily may be better predicted by attitude, SN and PBC alone, without the addition of SE. It may be that SE is not as important to predicting carer intentions to support CYPID, compared to carers of TDCYP (Chambers et al. 2007). Although not as good as the original model, the extended model did demonstrate a good fit (as indicated by CFI and RMSEA indices), similarly indicating that measures represented latent variables. Measures used were intended for TDCYP, including the SE measure (West et al. 2009; West et al.
2010) which included but did not specifically focus on self-efficacy in relation to meeting healthy diet requirements. It may be that the future development of tools designed for CYPID could improve the fit of this extended model. SEM provided evidence based on individual pathways within the extended TPB model, that only Intention was a significant predictor of behaviour (p<0.001). Similar to the original model, all four predictor variables did not significantly predict intention, suggesting influential variables, not captured in the present study, may be present. Correlations indicated that SE was positively and significantly related to intention, but unrelated to behaviour, whereas the full extended TPB model, in which SE predicted intention, showed an improved fit when SE also predicted behaviour, as per some past research (Fila et al. 2006). Given some mixed findings from both past and present research, future research may explore the potential roles of mediator or moderator variables in affecting the relationship between SE and behaviour, during TPB dietary research.

**Past & future behaviour**

Past and future behaviour and intention all correlated positively and significantly, as expected, although the relationship was stronger between intention with past than future behaviour. Best fitting TPB models were achieved using past rather than future behaviour, contrary to previous TPB dietary research (Armitage et al. 1999). These findings may be the result of 58.4% missing data and non-normality on data measuring behaviour at Time 2. The present study demonstrated positive and significant correlations between parents’ reports of child’s diet and parental encouragement of
healthy eating behaviours, indicating similar outcomes regardless whether the behaviour of the caring or the cared for population was measured.

**Strengths**

The use of SEM (confirmatory rather than exploratory, given the sound TPB theoretical rationale), which allows relationships between latent variables to be explored, may be considered a strength of this study (Coffman et al. 2005). The sample size was sufficient for this analysis, with the voluntary sector being an especially fruitful source of recruitment. In order to address some limitations of past research in this area, behaviour was measured at two time points (Jenkins et al. 2011; Mcgillivray et al. 2013), weight outcomes (BMI) were included (Jenkins et al. 2011), a measure of children’s eating was included (Mcgillivray et al. 2013), and an established theory was used, allowing easier comparisons with other studies (Mcgillivray et al. 2013). The present research provides additional evidence to support the use of TPB to predict the dietary behaviour of one group in relation to another, a newly developing area where only four other studies are available (Astrom et al. 2006; Andrews et al. 2010; Chambers et al. 2007; Jenkins et al. 2011).

**Limitations**

Parcelling and MLR, in addition to listwise deletion during SEM, were intended to ameliorate the effects of missing data and non-normality on some variables. Past behaviour was used in place of future behaviour (Ajzen 1991), where data was missing.
Internal reliability of SN was not adequate, and this may have been reflected in correlation findings, although SN has been reported as a weak predictor of intention previously (Armitage et al. 2001; Povey et al. 2000; Chambers et al. 2007). The research was limited to the availability of TPB and SE measures not designed to suit CYPID (an area for future research). Although the behaviour being examined was broadly defined as parental encouragement of child healthy eating, this was not worded in an identical way between LBC and TPB tools, and the LBC tool included additional behaviours, which may have reduced goodness of fit of the extended model. The development of more appropriate measures, including multi-item rather than some single-item measures, may in future result in research in which model fit is improved. T2 non-completers scored significantly lower in their SE, non-completion perhaps reflecting their difficulty in finding time to complete the second survey. Time 1 completers data was made up of approximately half of participants who completed a T2 survey (and having higher SE), as well as the other half who did not do so (having lower SE), so this combination is likely to provide SEM findings which convey a realistic picture, that SE did not significantly regress onto intention or behaviour. Self-report rather than objective measures may be affected by desirability biases. Attempts were made to reduce attrition, by sending email reminders. Using longer matching codes would have resulted in less replication, which would have allowed more individuals T1 and T2 surveys to be matched and therefore included. Parents were mainly sourced from the voluntary sector or online community, with comparatively few being recruited successfully directly from educational or clinical sources. This could possibly reflect biased findings due to a
difficulty for clinical populations in participating, or alternatively the increased ease of those recruited online in using an online survey. Mainly mothers completed the survey, perhaps reflecting their greater involvement in research relating to their child; It would have been interesting to have more fathers additionally expressing views. Other limitations of the study included reliance on parents/ carers to validate that their child has an ID before proceeding with completing the questionnaire.

**Implications for policy and practice**

International policies recommend inclusion of information about how generic policies can be adapted to the needs of CYPID (WHO 2010; WHO 2012). National childhood obesity policies recommend inclusion of parents in interventions for TDCYP, and addressing diet as part of a multi-component intervention (NICE 2006; SIGN 2010; NMHRC 2013). The present research is indicative that there is not sufficient evidence that non-medical obesity interventions for CYPID should focus on addressing TPB variables of parental attitude, SN, PBC, or the present additional SE variable. This information could perhaps be added to future national policies, so as to disseminate findings about what will and will not be useful when developing effective interventions for this population.

The present research provides some additionally helpful information which may be informative to those developing interventions for this population. The following points are also relevant to clinical guideline recommendations to assess and cater to the needs
of disabled individuals when providing obesity interventions (NICE 2006; SIGN 2010). Firstly, socio-demographic data provides evidence of the clinical need to address both over and under-weight amongst CYPID, as well as over-weight amongst parents of CYPID. Prevalence of obesity (30.2 %), overweight (10.1%) and underweight (12.4%), were similar to those from literature (e.g. Stewart et al. 2009), all demonstrating more unhealthy weights for CYPID than TDCYP, and demonstrating representativeness of findings from present data. Public health measures are rightly focused on tackling obesity due to trends towards increasing weight (Scottish Government 2011). However, those driving policies may benefit from increased awareness of the additional clinical need to address underweight amongst this population. 52% of parents of CYPID were overweight or obese, compared to 23-28% of the UK adult population (IOTF 2011), this being an additional risk factor for their child’s weight (Skouteris et al. 2011). Secondly, dietary interventions should give consideration to the fact that high numbers of CYPID (26.3%) from this study had special diets. Thirdly, exercise interventions being developed should acknowledge that high numbers of CYPID (45%) from this study were rated as having mobility difficulties. Fourth, the majority of CYPID from this study (76.8%) scored in the clinically significant range in terms of their problematic weight related behaviours, and so special consideration to the management of such behaviours should be incorporated into weight interventions for this population. A fifth point to note for those developing interventions for this population, is that 58.4% of parents in the present research reported clinically significant low SE in managing these behaviours, the latter combination being characteristic for children who are obese (West et al. 2009).
Whilst the present research suggests a focus on improving parental SE will not necessarily improve parent’s intentions or behaviour in encouraging their child’s healthy eating, developers of interventions should be made aware of this clinical need, such that parents may benefit from some additional support. Clinicians, drivers of policy, and those developing interventions, may benefit from aiming to address some of these additional challenges faced by this group, in the quest towards improving the physical and emotional health and life span for CYPID.

**Key Findings and Recommendations**

This research provides evidence that both the original and extended TPB models were suitable for use when researching healthy eating amongst CYPID, and that the original was the better of the two models. Despite their suitability according to SEM, both versions of the TPB model showed significant pathways from intention to behaviour only. All four predictor variables explored (parental attitude, SN, PBC, SE) did not significantly affect either intention or behaviour, and therefore there is not sufficient evidence to recommend that interventions target these variables for this population. However, a number of areas of additional challenge have been identified which could be recommended as suitable to incorporate into future interventions to be developed for this group. These include the clinical need to address unhealthy weight for CYPID (and their parents), adapting dietary and exercise interventions with consideration to special diets and mobility difficulties, as well as addressing clinically significant children’s weight-
related challenging behaviours, and supporting those parents who have clinically low SE in managing these behaviours.

Measurement tools for TPB and SE require to be developed specifically for CYPID. Future research is required to identify which additional variables contribute towards parent’s intentions and actual encouragement of their child’s healthy eating, amongst CYPID.
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Source of Funding: None.

Conflict of Interest: None
References for Whole Thesis


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Appendix 1: Systematic Review Journal Article Author Guidelines, for Journal of Pediatrics

The following was downloaded from http://www.jpeds.com/authorinfo during June 2013:

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A list of abbreviations and acronyms that appear >3 times should be included in the manuscript, along with the expansion of each. All abbreviations and acronyms should be expanded, followed by the abbreviation or acronym in parentheses, upon first use in the abstract, as well as in the first use in the body of the manuscript. All subsequent uses, including tables and figures, should use the abbreviation or acronym. Because abbreviations and acronyms are designed to assist readers, they should be limited to those defined in the AMA Manual of Style, those that are commonly used by general pediatricians, and those that shorten the names of study groups.

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Use nonproprietary names of drugs, devices, and other products, unless the specific trade name is essential to the discussion. The trade name may appear once in the Abstract and once in the Introduction or Methods section, followed by the nonproprietary name, manufacturer, and manufacturer location in parentheses; all other mention of the product must use the generic name. Trade names of drugs and other products must not appear in the article title.

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Laboratory values should be described in metric mass units. The International System of Units (SI units) should be provided in parentheses immediately after metric units. Conversion tables are available (see JAMA 1986; 255:2329-39 or Ann Intern Med 1987; 106:114-29).

References
References must be numbered according to order of appearance in the text and use superscript or parenthesized numbers in the text. For reference style, follow the Vancouver format set forth in "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" (http://www.icmje.org/), with journal abbreviations according to Cumulated Index Medicus. If the reference is to an abstract, letter, or editorial, place the appropriate term in brackets after the title. Citations should refer to primary analyses (ie, original content), instead of literature reviews and secondary analyses.

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For journal articles


For Articles in Press (online)

For books


For chapters in books

For websites
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**Article Types**

**Original Articles**

Full-length manuscripts for the Original Articles section of *The Journal of Pediatrics* must include a structured abstract of less than 250 words, to appear after the title page, with the following headings: Objective(s), Study design, Results, and Conclusion(s). The Objective(s) should put the study in context with the current literature (i.e., what is new, not textbook background information) and reflect the purpose of the study, that is, the hypothesis that is being tested or the question being asked. The Study design should include the study methodology, the setting for the study, the subjects (number and type), the treatment or intervention, principal outcomes measured, and the type of statistical analysis. The Results section should include the outcome of the study and statistical significance, if appropriate. The Conclusion(s) states the significance of the results and limitations of the study.

Original research articles should be approximately 18 double-spaced, numbered pages, including the title page, references, figures, and tables. Failure to comply with length restrictions may result in a delay in the processing of your paper. The following length targets are recommended for Original Articles:

- Structured Abstract: less than 250 words
- Introduction: 1 page
- Methods: 2-3 pages
- Results: 2-3 pages
- Discussion: 3-5 pages
- Graphics: 4 Tables + Figures total for OA
- References: 30

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Clinical and Laboratory Observations (CLOs) are either: (1) “case reports” that provide novel insight into pathophysiology, diagnosis, or treatment of an entity that does not represent a coincidental association; (2) small series of diagnostic or therapeutic interventions; or (3) brief, focused studies related to a topic of interest to pediatricians. Please note that CLOs are not designed to present information that is generally available in textbooks, even if the reported entity is novel. CLOs are designed to provide readers with new information and stimulate new approaches to diagnosis, clinical management, or research. CLOs should be approximately 9 double-spaced, numbered manuscript pages, including the title page, references, figures, and tables; the text should be less than 1000 words with a brief, unstructured abstract of less than 50 words. A combined total of 2 illustrations and tables and approximately 10 references are recommended.

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Letters to the Editor should pertain to papers published in *The Journal of Pediatrics* within the past year or to related topics and should not exceed 300 words. Provide a unique title for the Letter on the title page with complete contact information for the author(s). Double-space the text of the Letter. References, including reference to the pertinent article(s) in *The Journal*, should conform to style for manuscripts (see *References*).

**Medical Progress**

Authors who wish to propose a review article for the Medical Progress section must e-mail a proposal letter and formal academic outline of the manuscript (i.e., introduction, thesis statement, supporting ideas, and conclusion), identifying the article type for the Editors to assess, and outline to journal.pediatrics@cchmc.org for approval before submitting the full manuscript. (Editors will not assess full manuscripts prior to submission.) Medical Progress articles should focus on the latest advancements in rapidly changing fields. Practical guidelines, diagnostic algorithms, commentary of case management issues, and articles involving outcomes research may be appropriate for this section. Authors are encouraged to interpret cited works, which should lead to logical conclusions and recommendations. It is understood that some of these conclusions and recommendations will necessarily be tentative, but, if labeled clearly as such, are an essential part of the process. Medical Progress manuscripts should be approximately 15 double-spaced, numbered pages, including the title page, references, figures, and tables.

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Authors who wish to propose a manuscript for the Grand Rounds section must e-mail a proposal letter and formal academic outline of the manuscript (i.e., introduction, thesis statement, supporting ideas, and conclusion), identifying the article type for the Editors to assess, to journal.pediatrics@cchmc.org for approval before submitting the full manuscript. (Editors will not assess full manuscripts prior to submission.) Grand Rounds manuscripts should be informative and timely for the physician, containing up-to-date, but not necessarily new, unpublished data. Often these manuscripts will be reviews of topics of current interest, similar to Grand Rounds at a major academic center. Aspects such as innovative clinical management, new diagnostic techniques, and pathologic mechanisms should be stressed. Manuscripts for the Grand Rounds section may be prepared in traditional clinicopathologic conference (CPC) style or as a didactic discussion. Grand Rounds manuscripts should be approximately 16 double-spaced, numbered pages, including the title page, references, figures, and tables.

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proposal letter and formal academic outline of the manuscript (i.e., introduction, thesis statement, supporting ideas, and conclusion), identifying the article type for the Editors to assess, to journal.pediatrics@chmc.org for approval before submitting the full manuscript. (Editors will not assess full manuscripts prior to submission.) Workshop/Symposium Summary manuscripts should succinctly summarize scientific, single topic, consensus workshops/symposia that took place less than one year prior to submission and would be of interest to the readership of The Journal. A summary submitted for this section must be the only publication for the workshop; The Journal will not consider summaries that have been or will be published in whole or in part, excluding the workshop/symposium description/abstract in the meeting program.

Workshop/Symposium Summary manuscripts should be approximately 18 double-spaced, numbered pages, including title page, references, tables, and figures. If the manuscript significantly exceeds the suggested length target, it should be proposed as a sponsored Supplement to The Journal (see Supplement). An abstract should not be provided, and online only appendices, tables, and figures are not encouraged. However, authors are welcome to include videos, cartoons, audio clips, etc. as multi-media files (see Multi-Media).

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Submissions for the Announcements and Upcoming Events section must include the following information (* = required):

- Event Title *
- Dates *
- Host/Organizer/Sponsor *
- Location *
- Webpage *

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Journals and Institutions on Research Integrity Cases from the Committee on Publication Ethics (COPE)
Guidance from the Committee on Publication Ethics (COPE) regarding cooperation between research institutions and journals on research integrity cases can be found at
Checklist for Manuscripts


• Letter of submission
  o Names and complete contact information for 5-7 suggested reviewers  
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  o A statement that the manuscript has not been and will not be submitted to any other journal while it is under consideration by The Journal of Pediatrics;
  o A statement of any potential conflict of interest, real or perceived; this includes a description of the role of the study sponsor(s), if any, in: (1) study design; (2) the collection, analysis, and interpretation of data; (3) the writing of the report; and (4) the decision to submit the paper for publication. Include statements even when the sponsor had no involvement in the above matters. This information must also appear on the title page of the manuscript.
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  o List of key words not in the title;
  o Source of funding and conflict of interest statement, if applicable;

• Abstract (double-spaced), structured (less than 250 words) for Original Article or unstructured (50 words) for Clinical and Laboratory Observations
• Article proper (double-spaced), including
  o List of abbreviations (double-spaced)
  o References (double-spaced), on a separate page
  o Figure legends (double-spaced), on a separate page
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Updated April 2013
Appendix 2 – Systematic Review Excluded References

The journal guidelines request that the number of references is kept to 30. Therefore, details of the study that was not obtained (n=1) and excluded studies (n=29) have been recorded below. References for these studies are included in the whole thesis reference list.

Reference for single study which could not be obtained:

References for excluded studies
Excluded studies (n = 29) and reasons for each not being considered informative to the research question are presented below (Table 3). One main reason for exclusion (n = 14) was that participants included both adolescents and adults aged up to 26, therefore not being directly relevant to a specifically child and adolescent population.

Table 3, showing excluded references with reasons for exclusion:

<table>
<thead>
<tr>
<th>Reference</th>
<th>Reason for exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study</td>
<td>Criteria Failure</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Fleming’s description of unpublished study: “NIH-funded RCT with participants with intellectual disability (not just Down syndrome), aged 15-22. In this study we'll test the 6-month education and lifestyle intervention against a delayed treatment group, and then re-randomized completers to test a maintenance versus no maintenance intervention from months 6-12.”</td>
<td>Results won’t be available for 4 more years.</td>
</tr>
<tr>
<td>Gephart, E.F; Loman, D.G. (2013). Use of Prevention and Prevention Plus Weight Management Guidelines for Youth With</td>
<td>Did not meet inclusion criteria: Age range includes adults aged over 18 years</td>
</tr>
<tr>
<td>Title</td>
<td>Year</td>
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<td>----------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Reference</td>
<td>Summary</td>
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<td>-----------</td>
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</tbody>
</table>
Appendix 3 – Empirical Research Journal article Author Guidelines, for JARID (Journal of Applied Research in Intellectual Disabilities)

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1. GENERAL

The Journal of Applied Research in Intellectual Disabilities is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal’s requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

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2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to
the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

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Clinical trials should be reported using the CONSORT guidelines available at [www.consort-statement.org](http://www.consort-statement.org). A CONSORT checklist should also be included in the submission material ([www.consort-statement.org](http://www.consort-statement.org)).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: [www.clinicaltrials.org](http://www.clinicaltrials.org), [www.isrctn.org](http://www.isrctn.org). The clinical trial registration number and name of the trial register will then be published with the paper.

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OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author’s funding agency, or the author’s institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency’s preferred archive. For the full list of terms and conditions, see http://wileyonlinelibrary.com/onlineopen#OnlineOpen_Terms

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form available from our website at: https://authorservices.wiley.com/bauthor/onlineopen_order.asp

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal’s standard peer-review process and will be accepted or rejected based on their own merit.

4. SUBMISSION OF MANUSCRIPTS

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to http://mc.manuscriptcentral.com/jarid. If this is the first time you have used the system you will be asked to register by clicking on ‘create an account’. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as separate files.

Please upload:
1. Your manuscript without title page under the file designation ‘main document’.
2. Figure files under the file designation ‘figures’.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation ‘title page’.

All documents uploaded under the file designation ‘title page’ will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.
4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and Letters to the Editor are accepted. Theoretical Papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the Journal of Applied Research in Intellectual Disabilities should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
- Include all figure legends, and tables with their legends if available.
- Do not use the carriage return (enter) at the end of lines within a paragraph.
- Turn the hyphenation option off.
- In the cover email, specify any special characters used to represent non-keyboard characters.
- Take care not to use 1 (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
- Use a tab, not spaces, to separate data points in tables.
- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to The Concise Oxford Dictionary of Current English and units of measurements, symbols and abbreviations with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

The reference list should be in alphabetic order thus:


Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown et al. 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here: http://www.endnote.com/support/enstyles.asp
Reference Manager reference styles can be searched for here: http://www.refman.com/support/rmstyles.asp

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Preparation of Electronic Figures for Publication

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

Further information can be obtained at Wiley-Blackwell's guidelines for figures: http://authorservices.wiley.com/bauthor/illustration.asp.


Permissions: If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

Colour Charges: It is the policy of the Journal of Applied Research in Intellectual Disabilities for authors to pay the full cost for the reproduction of their colour artwork http://www.blackwellpublishing.com/pdf/SN_Sub2000_X_CoW.pdf

7. AFTER ACCEPTANCE

Upon acceptance of a paper for publication, the manuscript will be forwarded to the Production Editor who is responsible for the production of the journal.

7.1 Proof Corrections

The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.
Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website: 
www.adobe.com/products/acrobat/readstep2.html
This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

Proofs must be returned to the Production Editor within 3 days of receipt.

As changes to proofs are costly, we ask that you only correct typesetting errors. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately. Other than in exceptional circumstances, all illustrations are retained by the Publisher. Please note that the author is responsible for all statements made in their work, including changes made by the copy editor.

7.2 Early View (Publication Prior to Print)

The Journal of Applied Research in Intellectual Disabilities is covered by Wiley-Blackwell's Early View service. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have a volume, issue or page number, so Early View articles cannot be cited in the traditional way. They are therefore given a DOI (digital object identifier) which allows the article to be cited and tracked before it is allocated to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article.

7.3 Author Services

Online production tracking is available for your article through Wiley-Blackwell's Author Services. Author Services enables authors to track their article - once it has been accepted - through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit http://authorservices.wiley.com/bauthor/ for more details on online production tracking and for a wealth of resources include FAQs and tips on article preparation, submission and more.

For more substantial information on the services provided for authors, please see Wiley-Blackwell's Author Services.

7.4 Author Material Archive Policy

Please note that unless specifically requested, Wiley-Blackwell will dispose of all hardcopy or electronic material submitted two issues after publication. If you require the return of any material submitted, please inform the editorial office or Production Editor as soon as possible.

7.5 Offprints and Extra Copies

Free access to the final PDF offprint of the article will be available via Author Services only. Additional paper offprints may be ordered online. Please click on the following link, fill in the necessary details and ensure that you type information in all of the required fields: http://offprint.cosprinters.com/blackwell

If you have queries about offprints please email offprint@cosprinters.com
Appendix 4 - University Ethical Approval

Tutor comments:

Provisional Thesis Title: Parent’s intentions to provide a healthy diet in children with a learning disability: The application of a revised Theory of Planned Behaviour

Overall, this appears to be a good, robust and well-thought out study with clear relevance to service delivery – well done!

Although you have carried out a power analysis, I would have liked to have seen (in response to question 16 on the uni ethics form) details about the available sample size i.e. how many families there are in (South East Scotland) with children with LD. Without this information I wasn’t able to tell if there were any significant risks to you being unable to achieve the desired 84 participants. However, you do seem to have mediated this risk somewhat by the inclusion of recruitment from voluntary organisations.

Secondly, whilst you have clearly taken on board limitations from previous studies and attempted to address these, I would worry about a high attrition rate from your follow-up questionnaire? However, even if this turns out to be the case, this appears to be a solid piece of research with clear primary and secondary research questions that you should be able to answer.

Finally, I noticed on your IRAS form that you had ticked the box saying that you would have child participants. However, I think you have already submitted the form? Elsewhere, your description of the design of the study makes it clear what you intend to do.

-----Original Message-----
From: (University)
Sent: 22 December 2010 13:18
To: (Researcher)
Cc: (University)
Subject: Thesis Ethics Comments

Hi (Researcher)

Please see attached comments relating to your thesis ethics form.

Best wishes for Christmas and the New Year.
(University)
Researcher’s response to above tutor comments:

Subject: RE: Thesis Ethics Comments
From: (Researcher email address)
To: (University)
Cc: (University)
Date: Wednesday, 22 December 2010, 13:33

Dear all,

Many thanks for so quickly looking at my form. I am glad to hear you think it sounds like a suitable thesis idea.

Regarding your comments:

1. I checked out the possibility of recruiting with a psychologist from (NHS Team), and she felt it would be a realistic number of participants. Having the voluntary sector on top should be helpful to top up though, as you have said.

2. (University) and I have already considered there is likely to be a high attrition for the second questionnaire. I will do what I can to address this by emailing participants one month after they complete the first questionnaire, to remind them to complete the time 2 questionnaire. We felt it was better to at least try to obtain some information about actual diet, rather than just intended diet, because this was a criticism of past research in the area.

3. I have already submitted the form. Although I am not actually recruiting children, (Name) from Ethics/IRAS, recommended that I should tick this box, because parents are being recruited, and that I could explain this if asked about it at the panel.

I hope this answers your queries. If there is anything else I should consider, please email my personal yahoo account (Researcher’s email address)

Many thanks again, and festive greetings!

(Researcher’s name)
Appendix 5A – NHS ‘REC’ ethical approval

05 April 2011

Dear [Name],

Study title: Parent’s intentions to provide a healthy diet in children with a learning disability: The application of a revised Theory of Planned Behaviour

REC reference: 10/S1103/65

Thank you for your letter of 30 March 2011, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information was considered by the chair and vice chair on behalf of SESREC 3

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk).

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>30 March 2011</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaire: LBC</td>
<td>amended</td>
<td>10 March 2011</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>14 December 2010</td>
</tr>
<tr>
<td>Participant Information Sheet: PIS</td>
<td>2</td>
<td>10 March 2011</td>
</tr>
<tr>
<td>REC application</td>
<td></td>
<td>14 December 2010</td>
</tr>
</tbody>
</table>

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/S1103/65 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project

Yours sincerely

(Name and email address removed to protect anonymity)

“After ethical review – guidance for researchers” [SL-AR2]

Copy to:

[R&D office for NHS care organisation at lead site]
Appendix 5B – NHS ‘REC’ minor amendment approval letter

Scotland Research Ethics Committee 03

31 January 2012

Study title: Parent’s intentions to provide a healthy diet in children with a learning disability: The application of a revised Theory of Planned Behaviour

REC reference: 10/S1103/65
Amendment number: 
Amendment date: 23 January 2012

Thank you for your email of 23 January 2012, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questionnaire: Theory of Planned Behaviour TPB</td>
<td>TPB revised</td>
<td>23 January 2012</td>
</tr>
<tr>
<td>Notification of a Minor Amendment</td>
<td></td>
<td>23 January 2012</td>
</tr>
</tbody>
</table>

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.
Yours sincerely

(Name of contact from Ethics)

Committee Co-ordinator

(Email address for contact from Ethics)
Appendic 5C – NHS ‘REC’ substantial amendment approval letter

16 August 2012

(Area) Scotland A REC
(Address of Ethics)

(Name and address of researcher)

Study title: Parent’s intentions to provide a healthy diet in children with a learning disability: The application of a revised Theory of Planned Behaviour

REC reference: 10/S1103/66
Amendment number: 1
Amendment date: 05 August 2012

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion
At present the paperwork contains a mixture of learning disability in full and LD. Learning disability should be in full throughout or, if to be abbreviated, LD should be defined at first use.
Prader willi should be Prader-Willi or better Prader-Willi syndrome.
There is a typo in the disadvantages and risk paragraph – should be event not even.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents
The documents reviewed and approved at the meeting were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary of Changes</td>
<td></td>
<td>10 July 2012</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>3.0</td>
<td>10 July 2012</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>3.0</td>
<td>10 July 2012</td>
</tr>
<tr>
<td>Protocol</td>
<td>2.0</td>
<td>10 July 2012</td>
</tr>
<tr>
<td>Notice of Substantial Amendment (non-CTIMPs)</td>
<td></td>
<td>05 August 2012</td>
</tr>
</tbody>
</table>

Membership of the Committee
The members of the Committee who took part in the review are listed on the attached sheet.
R&D approval
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/S1103/65: Please quote this number on all correspondence

Yours sincerely,

Names removed to protect anonymity

Members of the REC

<table>
<thead>
<tr>
<th>Name</th>
<th>Position (or reason for attending)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Specialist</td>
<td>Expert</td>
</tr>
<tr>
<td>Lay Member</td>
<td>Lay Plus</td>
</tr>
<tr>
<td>Physician</td>
<td>Expert</td>
</tr>
</tbody>
</table>

REC meeting on 10 August 2012
Appendix 5D – NHS ‘R & D’ ethical approval letter

University Hospitals Division

(Researcher and Ethics names and addresses)

REC No: 10/S103/93
CTA No: N/A
Research: N/A
Protocol No: dated 14 December 2010

I am pleased to inform you that the study has been approved for NHS for you may proceed with your research, subject to the conditions below. This letter provides the specific approval for NHS.

Please note that the NHS R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or research input required of NHS. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the NHS, where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely
Appendix 5E – NHS ‘R & D’ ethical substantial amendment approval letter

University Hospitals Division

2 October 2012

REC No: 10/S1103/65
R&D Project ID No: 2011/C/PNLD/01
Amendment: Substantial amendment No.1 dated 10 July 2012
Title of Research: Parent’s intentions to provide a healthy diet in children with a learning disability: The application of a revised Theory of Planned Behaviour

I am writing in reply to recent correspondence in relation to an amendment(s) to the above project and the subsequent updated documents as follows:

- Summary of changes, dated 10 July 2012
- Protocol, version 2 dated 10 July 2012
- Participant information sheet, version 3 dated 10 July 2012
- Letter of invitation to participant, version 3 dated 10 July 2012

We have now assessed any consequential changes and can confirm that management approval is extended to cover the specific changes intimated.

Yours sincerely
Appendix 6A – Council approval letter to recruit from city schools

I am writing in response to your application requesting permission to undertake research in schools in [Redacted].

Your request has been considered, and I am pleased to inform you that you have been given permission in principle to undertake your research. I must stress that it is the policy of this Authority to leave the final decision about participation in research projects of this kind to Head Teachers and their staff, so that approval in principle does not oblige any particular establishment to take part.

Please be aware that if you are approaching special schools, some parents may self select not to participate for a variety of reasons (e.g., may have literacy issues themselves). Can you clarify that it is parental names you need from the school.

I request that you forward a copy of your completed findings to me when they become available. In this case an electronic summary of your thesis would be preferred. Your work may be of interest to a number of staff in the Children and Families Department.

I would like to thank you for contacting the Children and Families Department about your work, and wish you every success in the completion of your project.

Yours sincerely

[Redacted]
Appendix 6B – Council approval email to recruit from rural schools

RE: FW: Thesis permission to approach East (Area) special schools

Wednesday, 4 April, 2012 15:12

From: (School email address)

To: (Researcher’s email address)

Hi (Researcher’s name),

We do not have ‘special’ schools… (details about how schools operate in this area)…

I would suggest that you send your letter to all our schools.

Kind regards

(Name)

Department of Education and Children’s Services
(Address)
Appendix 7A – Participant Information Sheet and various invitation letters to recruit at Time 1

NHS version of Participant Information Sheet:

(nhs area logo)
Version 3 and date 10.07.12

Participant Information Sheet

‘Your child: Eating and Behaviour’

Parent’s intentions to provide a healthy diet in children with a learning disability: The application of a revised Theory of Planned Behaviour

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Parents of children who have a Learning Disability (LD) are being asked to complete a survey about their child’s eating habits and behaviours, and about their own beliefs and attitudes in relation to this. Parents will be invited to participate in this study regardless of their own child’s weight.

The study will use an online survey. (Researcher), Trainee Clinical Psychologist, will examine the results of the surveys. It is hoped that the study will enable the researchers to better understand the relationships between their children’s eating-related behaviours and parental beliefs/attitudes. With increased understanding, we may be able to better support parents to manage their
children’s diet-related behavioural problems. We may also be able to better understand why obesity is more likely to develop amongst this population.

Why have I been asked to take part?
You have been asked to take part because we believe that you are a parent of a child who has a LD, and is aged 5 to 18 years. If you continue to live with your child, and you have some influence over their diet, you are suitable for inclusion in this study. If your child has Prader-Willi syndrome or is tube fed, please do not take part. This is because both of these situations would cause your child to be on a carefully controlled diet.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?
You are invited to complete an online survey, using the link below. The questionnaire will take approximately 25-30 minutes to complete. If you choose to complete the online survey, it will be assumed that you are providing consent to take part in the study. One month later, you will be emailed, and asked to complete a shorter follow-up questionnaire, which will take only 5 minutes to complete. Some questions will ask whether your child complains, etc, and non-verbal communication IS included, and considered to be important in your response.

What are the possible benefits of taking part?
It may be that useful practical suggestions for specific supports emerge that could be implemented to help parents of children or young people who have a LD. It is also possible that a better understanding of the challenges faced by parents of children or young people who have a LD may be gained by the researcher.

What are the possible disadvantages and risks of taking part?
It is not thought that there are many disadvantages. In the extremely unlikely event that you feel upset as a result of completing the survey, please seek support from the clinician working with your child.

What happens when the study is finished?
If you wish to remain informed about the study, please email (researcher) (email address below). Any feedback would not be specific to you, because the questionnaires are completed anonymously. See below for how results of the study will be used.
Will my taking part in the study be kept confidential?
All the information we collect during the course of the research will be kept strictly confidential and there are strict laws which safeguard your privacy at every stage. The online questionnaire will ask for your email address, and no other personal information. Questionnaire data will be stored online securely.

What will happen to the results of the study?
The study will be written up as a Doctoral level thesis and may possibly be presented at conferences.

Who is organising the research and why?
Researcher, Trainee Clinical Psychologist, is organising this research, as part-fulfilment of her Doctorate in Clinical Psychology. Whilst carrying out this research, Researcher benefits from supervision by Clinical Psychologists working at University of Edinburgh, and NHS (area).

Who has reviewed the study?
The study proposal has been reviewed by University of Edinburgh. NHS Ethical approval has been obtained as has NHS R&D permission.

If you have any further questions about the study, please contact Researcher by email: (Email address)

If you wish to provide any anonymous feedback about how the study has been managed or carried out, please contact the researcher via email.

If you would like to discuss this study with someone independent of the study please contact (Name of contact person) by email: (Email address)

The NHS (area) Complaints Team is based at:

(Contact details)
Participant Information Sheet

‘Your child: Eating and Behaviour’

Parent’s intentions to provide a healthy diet in children with a learning disability:

The application of a revised Theory of Planned Behaviour

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Parents of children who have a Learning Disability (LD) are being asked to complete a survey about their child’s eating habits and behaviours, and about their own beliefs and attitudes in relation to this. Parents will be invited to participate in this study regardless of their own child’s weight.

The study will use an online survey. (Researcher), Trainee Clinical Psychologist, will examine the results of the surveys. It is hoped that the study will enable the researchers to better understand the relationships between their children’s eating-related behaviours and parental beliefs/attitudes. With increased understanding, we may be able to better support parents to manage their children’s diet-related behavioural problems. We may also be able to better understand why obesity is more likely to develop amongst this population.
Why have I been asked to take part?
You have been asked to take part because we believe that you are a parent of a child who has a LD, and is aged 5 to 18 years. If you continue to live with your child, and you have some influence over their diet, you are suitable for inclusion in this study. If your child has Prader-Willi syndrome or is tube fed, please do not take part. This is because both of these situations would cause your child to be on a carefully controlled diet.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?
You are invited to complete an online survey, using the link below. The questionnaire will take approximately 25-30 minutes to complete. If you choose to complete the online survey, it will be assumed that you are providing consent to take part in the study. One month later, you will be emailed, and asked to complete a shorter follow-up questionnaire, which will take only 5 minutes to complete. Some questions will ask whether your child complains, etc, and non-verbal communication IS included, and considered to be important in your response.

What are the possible benefits of taking part?
It may be that useful practical suggestions for specific supports emerge that could be implemented to help parents of children or young people who have a LD. It is also possible that a better understanding of the challenges faced by parents of children or young people who have a LD may be gained by the researcher.

What are the possible disadvantages and risks of taking part?
It is not thought that there are many disadvantages. In the extremely unlikely event that you feel upset as a result of completing the survey, please seek support from friends and family.

What happens when the study is finished?
If you wish to remain informed about the study, please email (researcher) (email address below). Any feedback would not be specific to you, because the questionnaires are completed anonymously. See below for how results of the study will be used.

Will my taking part in the study be kept confidential?
All the information we collect during the course of the research will be kept strictly confidential and there are strict laws which safeguard your privacy at every stage. The online questionnaire will ask for your email address, and no other personal information. Questionnaire data will be stored online securely.

**What will happen to the results of the study?**

The study will be written up as a Doctoral level thesis and may possibly be presented at conferences.

**Who is organising the research and why?**

*Researcher*, Trainee Clinical Psychologist, is organising this research, as part-fulfilment of her Doctorate in Clinical Psychology. Whilst carrying out this research, *Researcher* benefits from supervision by Clinical Psychologists working at University of Edinburgh, and NHS *(area).*

**Who has reviewed the study?**

The study proposal has been reviewed by University of Edinburgh. NHS Ethical approval has been obtained as has NHS R&D permission.

If you have any further questions about the study, please contact *Researcher* by email: *(Email address)*

If you wish to provide any anonymous feedback about how the study has been managed or carried out, please contact the researcher via email.

If you would like to discuss this study with someone independent of the study please contact *(Name of contact person)* by email: *(Email address)*
Dear Parent,

I am inviting you, as a parent of a child with a learning disability, to complete a short online survey. The survey is about your child's eating habits and behaviours, and your role as a parent in relation to these. As a Trainee Clinical Psychologist, I am carrying out this research as part of my doctoral training. If you decide to go ahead and complete the survey, it will be assumed that you are giving consent to taking part. For more information about this study, please go to: [https://www.XXX](https://www.XXX)

I would be grateful if you would be willing to complete the online survey, which can either be accessed via the above link, or you can go to: [https://www.XXX](https://www.XXX)

Many thanks for taking the time to consider participating in my study.

Yours sincerely,

*Researcher (Trainee Clinical Psychologist)*
SCHOOLS PARENT INVITATION LETTER

‘Your child: Eating and behaviour study’

Dear Parent,

I am inviting you, as a parent of a child with a learning disability, to complete a short online survey. The survey is about your child’s eating habits and behaviours, and your role as a parent in relation to these. As a Trainee Clinical Psychologist, I am carrying out this research as part of my doctoral training. For more information about this study, please go to:

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I would be grateful if you would be willing to complete the online survey, which can either be accessed via the above link, or you can go to:

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Many thanks for taking the time to consider participating in my study.

Yours sincerely,

Researcher (Trainee Clinical Psychologist)

VOLUNTARY SECTOR ORGANISATION EMAIL INVITATION SEEKING PERMISSION TO RECRUIT

Dear Sir/ Madam,

I am a Trainee Clinical Psychologist from University of Edinburgh. My thesis is about healthy eating in children with a learning disability, and it involves asking parents to complete an online questionnaire. Please find attached a parent invitation to take part in my study, including a link to further information about my research, and the questionnaire itself (all online). I would really appreciate it if you could post the attached invitation on your organisation's newsletter/ website/ online members area/ email round members/ (i.e. whatever is possible!). Please let me know if/ when you post my link up. Please do not hesitate to contact me if you have any further questions about any of this!

Many thanks. I really appreciate your help with my research, and I will look forward to hearing from you soon.

(Researcher’s name)
VOLUNTARY SECTOR PARENT INVITATION

Health Eating Research

Are you a parent of a child with a learning disability, aged 5 to 18 years?

Do you have a few minutes to spare to fill out a brief questionnaire online? It is about your child's eating.

For more info: https://www.XXX

Survey: https://www.XXX

You will be helping a Trainee Clinical Psychologist to carry out research as part of training. Many thanks 😊

NON-UK VOLUNTARY SECTOR PARENT INVITATION

Health Eating Research

Are you a parent of a child with a learning disability, aged 5 to 18 years?

Do you have a few minutes to spare to fill out a brief questionnaire online? It is about your child’s eating.

For more info: https://www.XXX

Survey: https://www.XXX

Please note that this is a UK-based study, and so the **UK definition of Learning Disability is being used, i.e. IQ below 70, impaired daily living skills, before aged 18.**

You will be helping a Trainee Clinical Psychologist to carry out research as part of training. Many thanks 😊
Appendix 7B – Email invitations to complete Survey at Time 2

1st email (sent one month after Time 1 survey completed)

Title of email: Healthy Eating Research – this one is much shorter than last one!

Content of email:

‘Dear participant,

Many thanks for recently completing the online survey about your child’s eating. The final part of the survey can now be completed online. You may be pleased to hear it is much shorter than the last one! The link is:

https://www.XXX

Many thanks again for your time. I really appreciate it.

(name of researcher)

Trainee Clinical Psychologist’

2nd email (sent one week after 1st email)

Title of email: Healthy Eating Research – Thank you

Content of email:

‘Dear participant,

Thank you so much for recently completing both the longer first survey, followed by the brief second survey about your child’s eating. I really appreciate your contribution.

If you have not yet completed the second part of the survey, the link is below. It really is a lot shorter than the first questionnaire, and it will take less than 5 minutes to complete.

https://www.XXX

Many thanks again for your time. I really appreciate it.

(name of researcher)  Trainee Clinical Psychologist’
Appendix 8 - Authors permission to use LBC and TPB measures

**LBC questionnaire permission from West:**

Re: lifestyle behaviour checklist

Sent: Saturday, 11 December, 2010 8:36

From: (Author)

To: (Researcher)

...Thank you for your interest in the Lifestyle Behaviour Checklist. I am not aware of any further attempts to estimate the reliability of the measure. Only minor changes in wording were made from the original to the final version, and these were made to improve its validity. Therefore, I would not recommend use of the earlier preliminary version...

... A copy of the measure (New version), along with scoring information is attached....

**TPB questionnaire permission from Chambers:**

From: (Author)
Sent: 19 January 2012 11:17
To: (Researcher)
Cc:
Subject: RE: article

Hi (Researcher),

...There is no issue at all with you adapting the questions, in fact a couple of previous students studying Clinical Psychology at Edinburgh have adapted them for their doctoral studies...

With best wishes

(Author)
Appendix 9 - Participant involvement in research design

Thirteen individuals made contact with feedback for the researcher, five being from voluntary sector organisations and eight being parents, many expressing more than one item of feedback. One simply expressed a hope that the research goes well. Several contacted the researcher to clarify the inclusion criteria such as definition of LD, which was then provided. One enquired as to whether children’s views were being sought. The researcher explained that the parental role in encouraging healthy eating was the focus, but that any feedback from young people would certainly be valued. Three expressed frustration at under-fives being excluded, this being beyond the scope of the present research. The researcher temporarily considered including under-fives, and so emailed a new link to the same survey, with the age-range adapted to include under-fives. Because only one such survey became completed, this was unfortunately disregarded due to inadequate numbers of younger participants. One individual suggested that it would have been helpful to include a question on which diagnoses were present, in addition to LD. Due to this comment being made after most data was collected, it was not possible to include this question in the survey. However, it was agreed that this additional information could have been informative in checking whether the sample was typical and representative of the LD population in terms of additional diagnoses. One parent felt that children with autism should be excluded from the study due to a belief that they are so different to the LD population. The researcher responded that there are a large number of children with both diagnoses, and that their parent’s responses would certainly be valued within this research. One individual suggested that participants on special diets might alter results, although the PIS did highlight that those requiring special diets, such as those who are tube-fed or having
Prader-Willi syndrome, should not take part. Two individuals provided feedback that it was difficult to answer some of the questions due to their child being non-verbal. The researcher responded that non-verbal communication is extremely important and was intended to be viewed as such. Subsequently, to ensure parents were aware of this, the following sentence was added to the PIS: ‘Some questions will ask whether your child complains, etc, and non-verbal communication is included, and considered to be important in your response’. One source expressed that it was unfair to exclude those who may not have a computer, but it was acknowledged that everyone has access to computers at their local library. Three parents expressed frustration at the tick-box nature of the questionnaire, and the researcher made an apology for their experience, but explained that any additional comments could be emailed without these being linked to their questionnaire responses. Not allowing free text was intended to promote their anonymity, so as to reduce the possibility of participants identifying themselves. Four parents provided further information about their child’s eating habits, but it was not possible to include these here or to match these to their surveys due to anonymity and confidentiality. Whilst it was anticipated that the researcher may be contacted by supportive persons on behalf of potential participants who had literacy problems or other communication needs, no such requests were made for any special arrangements to be put in place.