Exploring Perceptions of Support Staff of Underweight in Adult Service Users with Learning Disabilities: An Interpretative Phenomenological Analysis Study

Nicky Godfrey

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School of Psychology
Faculty of Health and Medical Sciences
University of Surrey
Guildford, Surrey
United Kingdom
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Abstract of empirical paper

Background: Evidence suggests that underweight is associated with health consequences and has a higher prevalence among adults with learning disabilities compared to the general population. This research aimed to explore the perceptions of support staff of underweight in the adults with learning disabilities they support.

Method: Eleven support staff from residential learning disabilities services were interviewed. Interpretative phenomenological analysis was used to interpret the data.

Results: Three superordinate themes emerged that suggested a sense of uncertainty about supporting underweight residents, including that participants were holding conflicting ideas about underweight and were unsure about the causes and consequences of underweight. Participants perceived underweight in adults with learning disabilities as different from underweight in the general population, including that residents did not understand underweight. All participants described challenges associated with supporting underweight residents, including judgements that they might face and difficulties in encouraging underweight residents to eat. They also identified helpful strategies, including investigating underweight and trying different strategies to find one that was effective for the individual resident, and working as a team.

Conclusions: Overall, participants appeared to experience supporting underweight residents as complex and challenging, and fundamentally different from underweight in the general population. This is suggestive of an ‘us’ and ‘them’ approach, with participants’ understanding of causes of residents’ underweight possibly influencing how they responded to it. The challenges and judgements that participants described facing around supporting underweight residents can be seen in the context of
underweight appearing to be overshadowed by overweight, in services and in society. Uncertainty and lack of confidence around underweight could be addressed through the development of national practice guidelines for supporting underweight residents, alongside staff training about underweight to promote awareness of it. Further research exploring the perspectives of adults with learning disabilities and of other professionals could helpfully inform such interventions.
**Acknowledgements**

I would like to thank everyone who has supported me through this journey, including my clinical and research supervisors (the latter being Nan Holmes and Kate Gleeson) and my clinical tutors (Melanie Smart and then Catherine Huckle and Heinz Kobler).

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Part One - MRP Empirical Paper

Exploring Perceptions of Support Staff of Underweight in Adult Service Users with Learning Disabilities: An Interpretative Phenomenological Analysis Study

Statement of journal choice:


The Journal of Applied Research in Intellectual Disabilities (JARID) has been selected as a suitable peer-reviewed journal for publication of this paper. It has been chosen because it publishes original and applied research in the area of learning disabilities. This journal’s readership is international and multi-disciplinary, which is important as it is likely that this paper would be relevant and of interest to a variety of health and care professionals. The paper also fits with the journal’s emphasis on applied research, particularly as it is related to the journal’s aim of promoting valued lifestyles for people with learning disabilities. Underweight in adults with learning disabilities fits with a variety of the topics cited as covered in the journal, including physical health, mental health, quality of life and staff training.

10,000 words
Abstract

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**Conclusions:** Overall, participants appeared to experience supporting underweight residents as complex and challenging, and fundamentally different from underweight in the general population. This is suggestive of an ‘us’ and ‘them’ approach, with participants’ understanding of causes of residents’ underweight possibly influencing how they responded to it. The challenges and judgements that participants described facing around supporting underweight residents can be seen in the context of
underweight appearing to be overshadowed by overweight, in services and in society. Uncertainty and lack of confidence around underweight could be addressed through the development of national practice guidelines for supporting underweight residents, alongside staff training about underweight to promote awareness of it. Further research exploring the perspectives of adults with learning disabilities and of other professionals could helpfully inform such interventions.
Body weight is a subject on which much research has been conducted. Both obesity (a Body Mass Index, BMI, of 30 or over) and underweight (a BMI of 18.5 or under) (World Health Organisation, WHO, 2019) are associated with significant health concerns (WHO, 2002; WHO, 2009), although less is known about the health risks of underweight than obesity (Roh et al., 2014).

Obesity increases the risk of heart disease, stroke and cancer (WHO, 2002) and is associated with higher mortality rates (Rimmer & Yamaki, 2006). NICE guidelines advise on obesity prevention (NICE, 2015) and identification, assessment and management (NICE, 2014). Being underweight reduces immune system capacity, which can increase mortality from infectious diseases (WHO, 2002). The NHS (2017) identifies nutritional deficiencies and fertility problems resulting from underweight and recommends seeking medical advice. Underweight has been associated with increased mortality (Flegal, Graubard, Williamson, & Gail, 2005), however, no equivalent NICE guidelines are available for underweight.

Weight in adults with learning disabilities
People with learning disabilities are more likely to be both obese compared to the general population¹ (37.5% compared to 29.9%) and underweight (6.4% compared to 4.9%) (NHS Digital, 2019). More studies have explored the prevalence (Rimmer and Yamaki, 2006) and patterns (Bhaumik, Watson, Thorp, Tyrer, & McGrother, 2008) of obesity than underweight in adults with learning disabilities (Emerson, 2005).

¹ The term ‘general population’ has been used in this paper to refer to adults without learning disabilities as it is the phrase used most widely in the research literature.
**Obesity in adults with learning disabilities**

Research has uncovered factors associated with obesity in adults with learning disabilities, including being female (Bégarie, Maïano, LeConte, & Ninot, 2013), living independently (Rimmer & Yamaki, 2006) and having a less severe learning disability (Stancliffe et al., 2011). Unfortunately, causation cannot be inferred from these associations. Melville et al. (2008) hypothesised that women may have interests more likely to promote a positive energy balance, but did not offer evidence to support this. Others have related obesity to the increased choice and autonomy offered in domestic compared to institutional settings (Cartwright, Reid, Hammersley, Blackburn, & Glover, 2015), poor diet quality (Ptomey, Goetz, Lee, Donnelly, & Sullivan, 2013) and low physical activity (Hsieh, Rimmer, & Heller, 2014). Mulrooney (2014) stated that mental health conditions experienced by some people with learning disabilities may reduce their belief in their ability to lose weight or make lifestyle changes.

Findings associating obesity with lifestyle factors have led to interventions, as summarised in Spanos, Melville and Hankey’s (2013) systematic review of weight management interventions for obesity.

**Underweight in adults with learning disabilities**

There are fewer studies of underweight than obesity in adults with learning disabilities. In the general population, several factors, including eating disorders, mood or stress and medical conditions are considered possible causes of underweight (NHS, 2019), in addition to factors around body image and Western cultural values around thinness (van den Berg et al., 2007; Conner, Johnson & Grogan, 2004). These will be explored
further below. Some prevalence studies have identified factors associated with underweight in adults with learning disabilities, including younger age (Marshall, McConkey & Moore, 2003), male gender (Hove, 2004b) and more severe learning disabilities (Bhaumik et al., 2008). These studies did not explore causes of the higher prevalence of underweight so this remains unclear.

From a medical perspective, as with the general population, less is known about the health impact of underweight than obesity (Emerson, 2005). However, the Confidential Inquiry into premature deaths of people with learning disabilities (Heslop et al., 2014) found a lower median age of death for underweight than any other weight category.

No studies have evaluated interventions for underweight in adults with learning disabilities. Some authors who identified a higher prevalence of underweight made recommendations, although these were not based on research evidence. Bhaumik et al. (2008) recommended that weight monitoring attend to underweight as well as overweight. Emerson (2005) highlighted that strategies need to improve nutritional intake as well as reduce obesity. Gravestock (2000) recommended staff training on underweight in the context of eating disorders and physical, mental health and psychosocial co-morbidities.

_Understanding underweight in the general population_

Factors that are considered possible causes of underweight in the general population will be explored here due to the lack of literature on adults with learning disabilities.
Underweight can be understood in relation to mood, with evidence of a significant relationship between underweight and depression (De Wit, Van Straten, Van Herten, Penninx, & Cuijpers, 2009).

In eating disorders, underweight is understood in the context of anorexia nervosa, whereby underweight is maintained by an intense fear of gaining weight causing self-starvation (Nordbø, Espeset, Gullikson, Skårderud, & Holte, 2006).

Another explanation of underweight in the general population is around body image. The high value placed on thinness in Western cultures may cause people to compare their bodies with those in the media (van den Berg et al., 2007). Unhealthy weight control has been associated with body dissatisfaction (Conner et al., 2004). Together, this suggests that people may attempt to control their weight to reach the lower weight that they perceive society to prefer.

Another explanation of underweight is more medical. The NHS (2019) cite cancer and hyperthyroidism as the most common medical causes of underweight, with heart, liver, lung or kidney disease listed as less common causes of underweight.

**Understanding underweight in adults with learning disabilities**

The lack of research on underweight in adults with learning disabilities despite the likely higher prevalence, suggests that it might be helpful to consider how understandings of underweight in the general population apply to adults with learning disabilities.
The relationship between underweight and mood found in the general population has not been explored for adults with learning disabilities. Underweight in adults with learning disabilities has been associated with possible behavioural functions such as food refusal and self-induced vomiting (Hove, 2004b), which suggests that exploration of underweight from a psychological perspective is warranted.

There has been little research on eating disorders among adults with learning disabilities. Hove (2004a) identified a prevalence of 1.6% for anorexia nervosa in their sample of adults with learning disabilities. Gravestock (2003) proposed an altered classification system for eating disorders for adults with learning disabilities. However, his diagnostic criteria for anorexia nervosa have been criticised for removing the cognitive features that Jones and Samuel (2010) argued have been found in adults with learning disabilities.

In terms of relating underweight to body image, Ayaso-Maneiro, Domínguez-Prado, & García-Soidan (2014) showed that people with learning disabilities might have a distorted body image self-perception. However, Yoshioka & Takeda (2012) found no significant differences between ideal body shapes selected by individuals with and without learning disabilities.

Currently, there appears to be no literature investigating medical causes of underweight in adults with learning disabilities.
It may be that the increased prevalence of underweight among adults with learning disabilities compared to the general population needs to be understood differently from the causes outlined above so other possible factors will be explored below.

Evidence indicates significant health inequalities between adults with and without learning disabilities. Life expectancy is 14 years lower for men and 18 years lower for women with learning disabilities (NHS Digital, 2019). The Learning Disability Mortality Review (LeDeR, 2017) identified that many early deaths were ‘potentially amenable to good quality healthcare’ (p. 5). Elliott, Hatton and Emerson (2003) identified that people with learning disabilities in the UK had significantly worse health than the general population, including both underweight and overweight, and that they received inferior support from NHS services. Edwards et al. (2017) found that quality improvement was insufficiently implemented in improving access to physical healthcare for people with learning disabilities, suggesting that they continue to experience poorer health than the general population.

Scandals such as Winterbourne View exposed examples of inadequate care and abuse in some adult learning disabilities services (Parkin et al., 2018). The Serious Case Review reported two incidents of weight loss among service users at Winterbourne, alongside poor care around feeding (Flynn, 2012), suggesting that underweight may relate to inadequate support. Improved training for staff was recommended following this investigation (Bubb, 2014). The Learning Disability Core Skills Education and Training Framework (Skills for Health, 2016) outlined comprehensive learning needs for support staff. This emphasised the importance of staff awareness of health inequalities experienced by adults with learning disabilities and their role in supporting
people to ‘maintain good physical and mental health through nutrition, exercise and a healthy life style’ (p. 33), which is likely to include supporting healthy weight. Following the LeDeR review into premature mortality, the government committed to a public consultation on mandatory learning disability training for staff by March 2019 (Parkin et al., 2018). These events highlight the emphasis on improving support staff knowledge and competence in supporting the health and wellbeing of people with learning disabilities.

It may be that support staff are less aware of physical and mental health difficulties in adults with learning disabilities, which relates to the concept of diagnostic overshadowing (Bhaumik et al., 2008). There may be sociocultural reasons for underweight not being identified or addressed, related to media messages that being underweight is desirable (Gleeson & Frith, 2006). Evidence from the general population suggests that biopsychosocial variables (including individuals’ mood, their BMI and how they perceive sociocultural pressure around weight from the media and peers) can predict how accurately people perceive their own body size (McCabe, Ricciardelli, Sitaram, & Mikhail, 2006). All these factors could influence adults with learning disabilities and support staff, alongside cognitive and communication factors associated with learning disabilities that could influence both weight perception and ability to report any concerns.

Unfortunately, these possible causes of the increased prevalence of underweight in adults with learning disabilities are not currently supported by specific empirical evidence. Comprehensive literature searches completed for the literature review revealed a lack of research in this area. Although some prevalence studies attempted
to identify factors associated with underweight, their primary focus was generally on overweight in this population. The studies were also marred by methodological limitations and were generally of poor quality.

The lack of research and the health risks associated with being underweight suggests that it requires further investigation, initially through an exploratory study.

Some of the possible factors associated with underweight in adults with learning disabilities outlined above relate to the support they receive. As support staff offer direct care, if they are not noticing or responding to underweight, it may be that service users do not receive appropriate support. No research has been reported on how support staff perceive and respond to underweight in adults with learning disabilities so this is currently unclear. The purpose of this study was to explore this.

**Research aims**

The main objective of this study was to explore the perceptions of support staff of underweight in the adults with learning disabilities they support. This included how they understood, assessed and managed underweight. It was hoped that a greater awareness of how support staff perceived underweight would increase understanding of the apparent lack of emphasis placed on underweight among adults with learning disabilities compared to overweight.
Method

Methodology
This study used a qualitative design and inductive exploratory approach as little research has been conducted in this area. Interpretative Phenomenological Analysis (IPA) was chosen to explore and interpret participants’ individual experiences and the meanings attributed to them. IPA subscribes to social constructionism (the perspective adopted by this research), understanding individuals’ experiences as enmeshed with language and culture (Smith, Flowers & Larkin et al., 2009). See Appendix B for a full explanation of the choice of methodological approach.

A reflective account was completed during the research to develop awareness of how the researcher’s experiences and values might affect interpretations and analysis (Appendix C). This was used alongside discussions in supervision to support exploration of alternative perspectives and interpretations in the design, interview and analysis stages.

Recruitment
The study aimed to recruit support staff working with adults with learning disabilities within third sector or private learning disabilities services in the south of England. The target sample size was between four and ten participants, in line with recommendations for trainee IPA projects (Smith et al., 2009) and the idiographic emphasis on understanding individual experiences. Purposive sampling was used to recruit participants with shared experiences and for whom the topic would be pertinent. Recruiting participants from a small number of services within the same geographical
area was considered to offer a more homogenous sample, as recommended for IPA (Smith et al., 2009).

The following eligibility criteria were used to recruit participants:
- Currently employed as a support worker with adults with learning disabilities.
- 10 or more hours of 1:1 contact per week with adults with learning disabilities.
- At least six months of direct support experience with this client group.
- Responsibility for supporting service users to maintain good physical and mental health.
- Good understanding of and ability to express spoken English.

A senior clinical psychologist from a local NHS learning disabilities service acted as an external consultant and assisted in the identification of services. Emails outlining the research were sent to managers of four services to determine their interest in their service participating (Appendix D). Three managers consented to proceed so recruitment meetings with potential participants were arranged to describe the research and answer questions to support people to decide whether to participate. Participants were provided with an information pack, including an information sheet (Appendix E), a copy of the consent form (Appendix F) and the researcher’s contact details. Although the type of services to recruit participants from was not specified, all three services that agreed to participate were residential services.

**Participants**

Twelve participants from three residential learning disabilities services consented to participate. One participant withdrew before the interview, so eleven participants were
Eight participants were female. Participants’ ages ranged from 18-65, with three aged 18-25, four aged 26-35, one aged 36-45, two aged 46-55 and one aged 56-65. Ten participants identified as White British and one participant identified as White Other. One participant (Sam) did not have six months’ experience of working with adults with learning disabilities as they had not understood this requirement, however their data was included and considered in the context of their shorter experience. One participant had over six months but under one year’s experience, one participant had between one and two years’ experience and three participants had over two but under five years’ experience and five participants had over five years’ experience.

**Interview schedule**

A semi-structured interview schedule was created following guidance in Smith et al. (2009) (Appendix G) and considering the research literature. It was developed collaboratively with two supervisors, one with clinical experience of working in learning disabilities services and the other with qualitative research experience, including IPA. Possible interview questions were discussed with colleagues and other therapists (including the external consultant) experienced in working in learning disability services and the interview schedule was piloted with one of these colleagues. This interview was audio-recorded and reviewed and no revisions were deemed necessary.

Interview questions were designed to elicit relevant information for gaps identified in the current research evidence base and were used as prompts. The broad topics were participants’ understanding, assessment and management of underweight in the adults
they supported. As is usual in IPA, the exact form of each interview depended on the participant’s responses.

Interviews began with open questions about participants’ understanding of weight and their role. This was to support participants to feel comfortable by starting with questions they might feel more confident in answering and to accustom them to talking about weight.

Participants were asked to complete a short demographic questionnaire before the interview (Appendix I), with questions about age, ethnicity and gender as these have been found to influence weight and body size perception (Ålgars et al., 2009; Cochran, Neal, Cottrell, & Ice, 2012). This helped to situate the sample. Participants were asked during the interview to confirm their length of experience working with adults with learning disabilities.

**Procedure**

Interviews were arranged at each participant’s workplace and the interview topics were shared with participants before the interview, both verbally and in writing (Appendix H). This was to promote collaboration and support the process of informed consent. A verbal and written explanation of participants’ rights, including their right to withdraw any time prior to the commencement of data analysis, was provided before the interview and there was an opportunity to ask questions before signing the consent form.
Interviews lasted between 29 and 51 minutes, with an average length of 39 minutes, and were audio-recorded and transcribed verbatim by the researcher.

**Ethical issues**

The study was approved by the Research Governance Committee of the PsychD programme (Appendix J) and gained ethical approval from the Faculty of Health and Medical Sciences Ethics committee at the University of Surrey (Appendix K). Potential ethical issues were considered and addressed as part of this as weight could be a sensitive topic (Appendix L). Participants were advised that they should speak to their manager if they were concerned about their work, past or current. They were also advised of sources of support should they feel concerned about eating or weight difficulties of their own or someone else.

**Analysis**

Each interview was transcribed and analysed following Smith et al.’s (2009) process. The researcher listened to audio recordings and read and re-read the transcripts to become familiar with the data. Initial coding was completed for each transcript, to explore the semantic content and language use. Emergent themes were developed from these notes by considering possible interpretations of the participant’s meaning. These emergent themes were reviewed to identify connections between them. They were clustered into groups of similar themes, with supporting evidence from the transcript. Patterns and connections between themes across transcripts were identified to establish superordinate and subthemes for the group.
Quality assurance

The study was designed and conducted to meet the four characteristics of good quality qualitative research outlined by Yardley (2000) and clarified in the context of IPA by Smith et al. (2009) (Appendix M). Self-reflexivity, including reflective accounts, supported the researcher to consider the impact of their experiences and assumptions on the analysis and interpretation (Appendix C). A description of the analysis process (Appendix N) and excerpts of coded transcript showing this process (Appendix O) demonstrate the rigour, transparency and coherency of the analysis. Each participant’s initial themes are presented to support transparency (Appendix P).

Results

Interpretative Phenomenological Analysis of the interviews revealed 144 initial themes about the 11 participants’ understanding of underweight in residents (Appendix P). This analysis focussed on looking across participants’ data and initial themes for patterns and shared themes to answer the research question and make new contributions to knowledge (Appendices N and O).

Three superordinate themes emerged from the analysis along with contributory subthemes that together offer an understanding of how participants perceived underweight in residents (Table 1).
These themes are presented below, illustrated with verbatim extracts from participants’ transcripts. To aid readability, minor alterations have been made, including inserting words in square brackets to provide context. Ellipses in square brackets show where material has been omitted to make quotes more concise. Minor

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subthemes</th>
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<tr>
<td><strong>1.0 I’m just not too sure about underweight</strong></td>
<td>1.1 I think underweight is important but overweight gets more attention</td>
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<td>1.2 I don’t know why they’re underweight, it could be anything</td>
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<td>1.3 I don’t know much about the consequences of underweight</td>
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<td><strong>2.0 It’s different, they’re not like us</strong></td>
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<td>2.2 They’re underweight because of their learning disability</td>
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<td>2.3 They don’t notice underweight in the media</td>
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<td><strong>3.0 It’s hard to tackle underweight</strong></td>
<td>3.1 People might judge us</td>
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<td>3.2 The first thing is noticing</td>
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<td>3.3 At the end of the day, you can’t make them eat</td>
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<td></td>
<td>3.4 You have to find what works for that person, which can be challenging</td>
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<td>3.5 It’s a team effort</td>
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hesitations, tangents and utterances have been omitted, where these were not considered to remove significant meaning. Ellipses at the beginning or end of quotes show that participants were talking immediately before or after the quote. Pauses are illustrated by (pause) and underlining indicates words emphasised by participants. Gender neutral pseudonyms have been used to preserve anonymity, particularly due to the small number of male participants.

1.0 I’m just not too sure about underweight

The first superordinate theme captured participants’ uncertainty about underweight among residents. This included that participants were holding conflicting ideas about underweight, that they had an idea that underweight was important but overweight got more attention, in their services, health settings and in public discourses, prompting uncertainty. Uncertainty around underweight was also suggested by the fact that participants did not know what caused underweight and did not know much about the consequences of underweight.

Some participants said explicitly that they knew little about underweight, whereas for others it was apparent from their difficulty in answering questions. It has therefore been important to consider multiple meanings of ‘I don’t know’. These responses were explored within the interviews and questions were rephrased to attempt to ascertain whether ‘I don’t know’ related to not understanding the question or uncertainty around the topic.
1.1 I think underweight is important but overweight gets more attention

Participants appeared to be holding different ideas about underweight, which contributed to the sense of uncertainty. On the one hand, participants reported that underweight received little attention, particularly compared to the precedence given to obesity, within services and wider society. On the other hand, participants expressed a recognition that underweight was important and could be problematic. Some participants (including Nick and Jay) articulated both sides of this paradox, that underweight was neglected but probably still important.

Participants described the lack of attention given to underweight, in society and their services, which contributed to the uncertainty:

...I don’t know why but for some reason, underweight, it seems to, doesn’t get much (pause) attention [in society] (Jay)

...we don’t think about it [underweight] often [within the service]... (Nick)

Some participants contrasted the lack of attention on underweight with the increased attention paid to overweight in society and in health settings.

…overweight, you definitely know is unhealthy, but a lot of people don’t realise being underweight is unhealthy... (Lou)

...there is a lot more information out there in general for people being overweight than people actually being underweight.[...] When you go into the
doctor’s surgery, there’s signs up about being overweight. There’s never any information about being underweight (Ali)

Some participants placed this in the context of the desirability of underweight compared to overweight in society:

...society still gives the same message to everyone. That it’s better to be skinny than to be fat. And if you had to be one, you should be skinny (Nick)

Participants also reflected on the contrast between underweight and overweight within their services. Some participants believed that underweight was understood differently, being seen to be caused by illness unlike overweight:

...Being overweight, they’re fat, being underweight, there might be an illness...

(Lou)

Different attitudes towards underweight compared to overweight appeared to initiate different responses by support staff and health professionals:

...people definitely don’t treat it as urgent[...]The one who was very overweight, it was constant[...]Whereas the underweight one, obviously she was seeing the doctor for it, but it wasn’t dramatised as much (Nick)

GP didn’t seem overly concerned [about a resident’s weight loss] (Jay)
Alongside this lack of attention to underweight, some participants expressed an awareness that underweight was important, using language such as ‘serious’ and ‘dangerous’:

…she was seriously underweight. Like, dangerously so… (Nick)

…underweight also can be quite dangerous… (Alex)

This led participants to consider their responsibilities, with Lou describing their ‘duty of care’ around underweight.

The actions that participants took in response to underweight also suggested that they considered it important, as described in theme 3.4.

1.2 I don’t know why they’re underweight, it could be anything

The uncertainty about underweight among adults with learning disabilities appeared to be exacerbated by participants’ difficulties in identifying a clear cause of underweight among their residents.

Participants used a variety of phrases to illustrate this, including ‘there could be a whole host of reasons why they’re underweight’ (Jay); ‘it could be any number of things as to why they stop eating’ (Sam). Jo went as far as to say that the cause of underweight ‘could be anything’. 
Some participants listed a variety of reasons they believed may lead to residents being underweight:

...Have trouble with shopping; have financial problems; aren’t aware of healthy choices or what’s good for them; don’t understand the consequences if they don’t eat and drink properly. Don’t understand it’s going to make them poorly. And don’t have contact with people on a regular basis and no one intervenes... (Jay)

It could be worried about stuff, it could be family issues, where they’re missing family. It could be they’ve got a problem with another client, maybe another client keeps staring at their food... (Jo)

These reasons included psychological factors related to low mood (mentioned by six participants) and possible medical difficulties associated with underweight (mentioned by seven participants):

...it could be absolutely anything. They could be really depressed and we’re not realising that they’re depressed and they’ve just lost their appetite (Sam)

...It might be someone constantly with stomach pain or anything that doesn’t eat that much. It can be all sorts of things. Tooth pain for example, throat infections... (Chris)

Several participants appeared to hold a view that underweight could relate to poor care:
...it’s basically, bad practice. (Sam)

...They can become underweight because the staff don’t have the time. Like people who need assisted feeding. They could become underweight just ‘cos staff hasn’t got time or there’s not enough staff to feed them. Or the staff doesn’t persevere with the meal. It’s so easy to write on a piece of paper “Refused dinner”... (Lou)

Ali had a slightly different perspective, believing that the cause of underweight ‘depends on the individual’. Unfortunately, Ali struggled to explain this, again highlighting their uncertainty.

1.3 I don’t know much about the consequences of underweight

In addition to uncertainty about causes of underweight among residents, some participants were unsure about possible consequences of underweight.

This uncertainty was expressed by some participants explicitly but was also suggested by participants asking for clarification of related questions:

...I haven’t got a lot of knowledge about the consequences of being underweight

(Jay)

What do you mean [by the relationship between weight and health]? (Ashley)
Some participants had a view that there were health consequences of underweight:

...I think there’s a big relationship [between weight and health]. Some people think “Oh, you can be healthy at any size”, but I don’t think so… (Nick)

You’re not healthy if you’re a certain amount underweight (Lou)

Some participants appeared to have a sense that underweight was problematic but were not aware of specific health consequences of underweight, as they were for overweight. For example, Jay said both that ‘If anyone’s underweight by a large amount, you would have health problems’ but also ‘I don’t really understand what the risks to your health are if you are underweight’.

Other participants noted that people who were underweight looked ill, which seemed to be easier than identifying specific health consequences:

...it looks quite ill sometimes when people are too underweight (Alex)

Although some participants were able to name health difficulties that might be related to underweight, the way they talked about them included a lot of pauses and ‘um’s that suggested uncertainty:

Underweight, I would say, um, (pause) lethargic, maybe (pause). Yeah, energy. Um, lack of… (Frankie)
[Underweight] also can be unhealthy. Um, don’t know the names of them but I know you’ve got (pause) I think it’s bulimic? Bulimic? That is a health issue. Isn’t it?... (Alex)

2.0 It’s different, they’re not like us

In discussing underweight among adults with learning disabilities, many participants highlighted ways in which they believed it was different from underweight in the general population. This included beliefs that residents did not understand that they were underweight or why that might be problematic. Some participants expressed views that someone might be underweight because of their learning disability. A specific difference that some participants highlighted was that adults with learning disabilities did not notice underweight in the media in the same way they believed the general population did.

2.1 They don’t understand

A key difference compared to the general population was some participants’ belief that adults with learning disabilities ‘don’t realise they are underweight’ (Chris). Participants appeared to conceptualise this as a lack of cognitive capacity, with Jay stating that ‘people with learning disabilities don’t necessarily have that thought process. So they wouldn’t recognise [being underweight]’. Similarly, Alex said that ‘the understanding [around underweight] isn’t as clear’ noting for one underweight resident ‘I don’t think he knew that he had lost this weight’. Interestingly, Ashley described a resident whose understanding of underweight was ‘very up and down’, suggesting that this variable capacity may have exacerbated participants’ uncertainty.
Ashley also outlined challenges that residents’ lack of recognition of underweight could cause for staff:

…it’s quite harder to get, they don’t understand why you’re trying to get them to eat...

In addition to residents not understanding they were underweight, participants described that residents did not recognise possible health consequences of being underweight, with Nick summarising this as ‘I don’t think they really get it’. Some participants appeared confident that residents would not comprehend this, using phrases such as ‘they wouldn’t understand it’ (Charlie); ‘they wouldn’t know it’s harmful to them to be of that weight’ (Lou). Some participants said explicitly that adults with learning disabilities were different from the general population in that ‘people that have learning difficulties may not comprehend their difficulties of that [underweight]. And the results of being underweight. Whereas someone that hasn’t got a learning difficulties should understand’ (Jo).

Interestingly, some participants who thought that residents’ lack of understanding about underweight was different from the general population also expressed their own uncertainty about health consequences of underweight. For example, Charlie said both of the following quotes in their interview:

…whereas someone with no learning disabilities, you could quite easily say “Look, you’re underweight, you need to eat a bit more or do this or do that.”
They [residents] wouldn’t understand it if you said that they were underweight.

I can’t think of anything [health consequences of underweight] ...

Charlie may have illuminated a similarity between themselves and residents in being unable to name specific health consequences of underweight, but the difference may have been that adults with learning disabilities were not aware that being underweight could be problematic, which Charlie was.

2.2 They’re underweight because of their learning disability

Many participants outlined factors they associated with learning disabilities as having an influence on underweight. These were considered to be specific to learning disabilities so would not apply to the general population.

Four participants described the ‘rigid and routined [sic]’ (Charlie) nature of eating that they identified with adults with learning disabilities. Jay depicted residents as ‘really limited on what [food] they’ve tried’ while Nick discussed an underweight resident who ‘only eats the same thing every day’. Charlie appeared to relate this restricted range of food to sensory issues that they linked to a resident’s learning disabilities:

...he liked some textures, noodles and stuff, but wouldn’t eat anything else...
Some participants identified environmental differences that could have an impact on underweight. Residents’ learning disabilities meant both that they lived in different environments (residential settings) and that they interacted with these environments differently. Alex explained both sides of this, that the practices of residential services and residents’ experiences of them could impact on underweight:

...in residential care, ‘cos they have weekly food menus, just not liking the food. And not being given as many options as people like we would have...

...he didn’t want to be with the other residents. The environment was too much for him...

Lou related residents’ eating to concentration difficulties that they connected with learning disabilities:

...They might not have the concentration to sit and eat a dinner...They’re fast, rushy people...

Two participants thought that underweight was related to communication difficulties associated with learning disabilities:

They could be trying to tell you something’s wrong... (Jo)

...they’re not able to tell you that. So their not eating is just their way of communicating that something’s wrong... (Charlie)
Similarly, Ashley described communication and temperament difficulties influencing underweight in adults with learning disabilities and distinguished them from the general population:

\[\text{...It’s hard. They can’t tell you, and they’re more stubborn than us. They’re very stubborn. And they’re very structured so it’s certain ways in their head.}\]

### 2.3 They don’t notice underweight in the media

Another area of difference that participants highlighted between underweight in adults with learning disabilities compared to the general population was around media influence. Many participants believed that although people in the general population may value underweight due to the media, this was different for adults with learning disabilities.

Charlie thought that this was around residents not ‘pay[ing] attention to [media]’. Two other participants appeared to attribute the lack of influence of the media to residents’ poor understanding:

\[\text{...their normal understanding [of media] isn’t quite the same (Alex)}\]

\[\text{They wouldn’t understand or think that way... (Lou)}\]
Nick appeared to consider the potential influence of the media as more subtle, describing it as an ‘inference’ and again contrasting residents with the general population:

...obviously, more typical adults might get that from watching movies[...] and see all the beautiful people are skinny[...] [a] person with learning disability might not get that inference from the media...

These quotes illustrate language that participants used to differentiate residents from the general population, using words such as ‘normal’ and ‘typical’ to describe the general population.

### 3.0 It’s hard to tackle underweight

All the participants highlighted challenges associated with supporting underweight residents. Some participants talked about judgements about underweight from residents’ families and the public, implying that underweight could be linked to poor care. Participants believed that to address underweight, the first step is to notice it, and outlined difficulties connected with this. A frustration raised by all participants was being unable to make underweight residents eat. This led participants to emphasise the importance of finding what works for that person and working together as a team effort, including involving external professionals.

### 3.1 People might judge us

Some participants expressed feeling judged when supporting underweight residents.
Participants highlighted two perspectives on their experiences of feeling judged, that they thought people made assumptions about underweight possibly relating to poor care but also felt criticised for feeding underweight residents more:

...It is challenging because obviously you don’t want people to look at them and think “Oh, they’re, you’re not feeding them properly”. Or “You’re not doing your job right” or things like that. And it’s quite a sore subject. Especially if you tell a parent “Oh, your son’s underweight”. They might think that we’re not feeding them properly when actually, you know you are (Charlie)

...it’s very hard because there’s still a taboo around. I feel, when supporting her out in the community, that people were judging us for trying to make her bigger. Because I feel like people would say “Oh, why are you trying to make her fat? She’s so skinny, it’s fine.” I feel like there’s still a society thing (Nick)

Participants may have felt a pressure to show that despite the challenges of supporting underweight, they were doing everything they could, to avoid such assumptions about poor care. All the participants who related underweight to poor care distanced it by describing it as something that might happen in other services but not their own. Jay in particular contrasted inadequate practice as different from their service:

...they could go hours and days without eating, without anyone noticing. Whereas here, it’s 24 hour. We would know, if someone skipped breakfast, you’d make a note of that... (Jay)
3.2 The first thing is noticing

Participants emphasised being proactive and noticing underweight as the first step in supporting underweight residents.

Monitoring included weighing residents ‘regularly’ (Chris) and noticing underweight through residents’ appearance. This was often identified as keyworkers’ responsibility, although some participants highlighted that all staff have this duty:

...at the end of the month, we get the file and we update it all, they’re weighed...

(Jay)

...in each of our residents’ folders, we have next to the weight gain, we have the BMI chart for their height and their weight, and we can look if they’re in a danger zone... (Lou)

...main thing is definitely, we check their weight monthly. But you can also see it in them (Ashley)

You would [notice] their body. Visual is obvious straightaway... (Jo)

Some participants expressed challenges in identifying underweight, which Ali thought was more subjective than overweight:
I think it’s more of a judgement, because I can look at someone and think “You’re underweight.” They may not actually be underweight, they may be at healthy weight.

Other participants commented on difficulties around weight monitoring, with Nick describing how with one underweight resident ‘we couldn’t weigh him. He wouldn’t tolerate [going on the scales]’.

In addition to tracking weight change, some participants highlighted the importance of monitoring residents’ eating to enable them to notice any changes, particularly around refusing food:

...we’re well aware what they eat... (Jay)

Checking up on mealtimes. Completed meal, did not complete meal... (Jo)

3.3 At the end of the day, you can’t make them eat

Many of the difficulties highlighted were around being unable to ‘force them to eat’ (Sam), with Frankie saying ‘you can’t force-feed them’. Several participants described underweight residents as ‘refusing to eat’ (Ashley), with Lou explaining ‘if they don’t want to eat, they’re not going to eat’.

The difficulties around encouraging underweight residents to eat caused Nick to say ‘it’s very hard to tackle underweight’.
In addition to these challenges, some staff expressed a sense of responsibility for residents’ weight. For example, Lou said ‘I’m responsible for their weight loss [and] gain’. Participants appeared to consider themselves to be in a difficult position, that they were responsible for residents’ weight but it was hard to support underweight residents to improve this.

3.4 You have to find what works for that person, which can be challenging

Although it was experienced as challenging, participants did identify some helpful approaches when working with underweight residents, particularly around investigating weight loss and considering different strategies to identify what might best support that individual.

Some participants emphasised that following up on any weight loss identified, by communicating with colleagues and seeking advice, was an important early step, to decide what to do next:

_The deputy and manager obviously check the keywork, check the [weight] reports. And also (pause), we have staff meetings as well. If we do, and someone’s lost quite a bit, we’ll make sure everybody knows. And then it’s the GP (Frankie)_

Many participants described investigating possible causes of weight loss, with an emphasis on identifying any physical health causes that would be explored and addressed.
...You have to make sure it’s not something going on, (pause) health-wise. [...] You have to check everything with these guys ‘cos they can’t tell you (Ashley)

...when people lose weight, it’s normally a health issue. Especially if it’s a lot pretty quickly. And that would be always something that I would investigate first... (Charlie)

In addition to monitoring residents to identify underweight, participants highlighted the importance of increased observation and intervention once underweight had been identified. Some participants found it challenging to manage the monitoring, investigating and responding to underweight and then ‘getting the right advice [and] the right support’ (Ali):

*We’d monitor what they eat and drink. Definitely. That would be the first thing we do... (Jay)*

*...it’s quite challenging working with it and making sure that “Oh, that resident’s underweight. OK, let’s make sure they get a lot of food.” And make sure they’re not doing as much exercise. So they’re not going to the gym for a couple of weeks. It’s quite challenging. (Charlie)*

Despite investigation and monitoring, Nick described a resident for whom the team ‘could never pinpoint what it was that was causing her underweight’. This caused staff to have to ‘[try] everything to boost her weight’.
Chris described trying strategies that they had personal experience of:

...I will talk to my manager and my team lead and say “Look, I’ve done this myself, what do you think? Let’s try.” So we try, if it works, it works, if it doesn’t, dietitian is there to help us...

When discussing overcoming challenges associated with supporting underweight residents, Ashley said ‘We try everything. We try everything.’

For many participants, this involved ‘feeding them more’ (Lou), with Chris stating they would say to an underweight resident ‘take food all the time’.

Other participants described offering underweight residents different types of foods, to identify if they did not like the food, or if not eating had a different cause:

...if someone pushes away their food always offer them a different option. And then if they push it away again, it’s not because they don’t like the food. (Charlie)

Lou highlighted nutritional drinks as a particularly helpful supplement for older residents:

...There, the answer is, nutrition drinks rather than food. It’s all these little bottles of drinks. And sometimes that replaces even food (Lou)
Participants outlined various approaches to encouraging residents to eat more, including praise, prompts, reassurance and humour:

...praising when they have eaten dinner [...] Just make a joke, like “Oh, you must have been hungry”... (Alex)

...you can get something and eat it around them. And if you see them watching you. Right, let’s get another one of these. “Do you fancy one of these?”... (Jo)

...you would have to prompt her to eat more. Because we’re like “You have to put a bit of weight on, so you have to try and finish your dinner.”... (Nick)

Some participants outlined skills and attributes needed to encourage residents to eat using different approaches, which Charlie portrayed as ‘challenging’. Alex described trying to decide how best to support an underweight resident as ‘really hard for us’. When discussing challenges associated with supporting underweight residents, Frankie said ‘You need a lot of patience, (pause) to sort of, try and get around [the challenges]...’ Participants also emphasised the flexibility required to adapt approaches to support individual residents, including doing things differently from how they might otherwise:

...it’s about knowing the guys, you need to know how to support them. If they’re not supported properly, you will see it definitely in their weight... (Ashley)
If it was my daughter at the table, I would say, “Sit down. If you don’t eat it, I’m putting it away.” But when it’s someone underweight, you can’t say that. So you have to let them keep getting up and going back down. But you wouldn’t normally allow that. But you have to allow differences (Lou)

3.5 It’s a team effort

The actions taken to address underweight were combined with working together with other staff, from within and outside participants’ services.

Nick said ‘it’d pretty much be impossible to tackle it [underweight] on your own’ whilst Alex emphasised the importance of discussing underweight ‘in the staff meeting, for everyone to hear’. Participants discussed collaboration in different ways, from communicating with colleagues, to knowing when to seek external professional help, to developing and distributing a plan for staff.

We all work very closely together. The communication here is really good. So if someone did observe something, it would be shared with the staff straightaway (Jay)

...bring it up to the manager. If it was at the beginning of the month and the staff meeting wasn’t until the end of the month, they wouldn’t wait. They’d make sure it was said there and then[...]If it’s important, which it is, weight, they’d bring it up straightaway (Charlie)
Some participants emphasised the importance of seeking medical advice for underweight, which might relate to the finding above that some participants associated underweight with possible health difficulties:

...They [health professionals] need to know what’s going on (Ashley)

If we thought there was any health issues at all, we’d go straight to the GP. We wouldn’t hang around (Jay)

Many participants believed that having a shared plan to address the underweight that was understood and followed was important:

We just follow the plan we’re given, make sure this guy puts the weight back on... (Ashley)

...I would follow whatever, obviously there’d be a plan put in action. And then it’s up to everyone to adhere to that plan. No straying... (Jo)

These plans sometimes came from the GP or other health professionals, particularly if health concerns had been identified. Other participants described plans developed within the service, in meetings or by managers and keyworkers:

...my manager would be “Right, you need to do this now”... (Jo)

...we would get that, work out a plan between us... (Jay)
There’s *always* a plan, you know you’ve *always* got to get the health professionals involved (Ashley)

Participants expressed willingness to follow an agreed plan to achieve consistency in an area beset with uncertainty and complexities:

...we *do*, what we’re told to do, we follow. We really do...care’s *about* consistency to me (Jo)

**Discussion**

**Summary of findings**

This research employed a qualitative approach to explore support staff’s perceptions of underweight in adults with learning disabilities, particularly how they understood, assessed and managed underweight. This was prompted by the lack of research in this area despite the apparent higher prevalence of underweight among adults with learning disabilities than in the general population, and health risks associated with underweight.

This analysis revealed that in terms of understanding underweight in residents, participants felt a sense of uncertainty, including a lack of clarity around possible causes and consequences of underweight. It appeared that underweight was given lower priority than overweight but was still considered to be important. The results suggest that participants also understood underweight in people with learning disabilities to be different from underweight in the general population, in that adults
with learning disabilities did not understand they were underweight or the possible consequences of this. Participants also identified that underweight could be caused by factors specific to learning disabilities but that it was unlikely to be affected by media influence as some participants believed was the case in the general population. In terms of assessing and managing underweight, participants reported beliefs that it was challenging to work with underweight residents, that they faced judgements around failing in this but that the first step to improving the situation was to notice that someone was underweight. They expressed that they could not force underweight residents to eat so needed to devise a plan to support each individual. Working together, both within the service and with external professionals was thought to be helpful to overcome some of the challenges associated with addressing underweight.

**Exploration of findings**

In exploring how these findings contribute to understanding the views of support workers of underweight in adults with learning disabilities, it was important to consider how they relate to previous research and theory.

These findings suggest that participants understood underweight in adults with learning disabilities as different from underweight in the general population, including that they believed adults with learning disabilities lacked understanding of underweight and that the causes of underweight were different. These differences between residents with learning disabilities and the general population may be understood as part of an ‘us’ and ‘them’ perspective.
An ‘us’ and ‘them’ approach between support staff and people with learning disabilities has also been identified in other areas, including around sexuality. Here, it has been related to a lack of clear guidelines on supporting people with learning disabilities around sexuality (Löfgren-Mårtenson, 2004). The lack of guidelines on supporting underweight adults with learning disabilities may have led staff members to develop an ‘us’ and ‘them’ perspective to any differences they perceived. Cushing and Lewis (2002) criticised the ‘us’ and ‘them’ approach that they believed led to ‘discriminating, limiting stereotypes’ (p.174) applied to people with learning disabilities as a group and as individuals. They endorsed mutuality in relationships between people with learning disabilities and their caregivers as an alternative approach.

The understanding of underweight in adults with learning disabilities as different from underweight in the general population may also be seen in the context of participants’ caregiving roles. Research has suggested that there can be conflict between support workers’ values of autonomy for adults with learning disabilities and seeing service users as vulnerable (Windley & Chapman, 2010). It appeared that some participants believed that residents lacked understanding of underweight, including the consequences of not eating. This belief may have reinforced the view of residents as vulnerable and needing protection, which may have influenced participants’ responses towards underweight residents.

Participants also understood underweight amongst residents as different from the general population in terms of beliefs around causation. For example, two participants (Nick and Sam) mentioned anorexia nervosa as a possible reason why an adult in the
general population might be underweight but neither applied this to adults with learning disabilities. Instead, many participants believed underweight to be caused by factors specific to learning disabilities. Participants mentioned possible causes of underweight in this population, such as rigid routines, sensory issues and environmental factors, that have not been identified in previous literature. Some participants described that some residents may lack concentration to eat enough, which may cause underweight. Although concentration difficulties have been identified, particularly in people with profound learning disabilities (Lindsay et al., 1997), these do not seem to have been associated with underweight. Likewise, six participants thought that underweight could be related to low mood. Although depression is being increasingly recognised in people with learning disabilities, with weight loss being considered a symptom of depression (Munden & Perry, 2002), none of the literature exploring factors associated with underweight included low mood.

How participants understood underweight may have had implications for how they felt able to address it, with many participants citing possible medical causes they believed should be investigated and addressed initially. However, despite six participants relating underweight to low mood, none of them described supporting underweight residents psychologically as a way to overcome underweight. Although some participants suggested possible causes of underweight among residents, they also voiced uncertainty, expressing ‘it could be anything’. This uncertainty around the causes of underweight may have reduced participants’ confidence in addressing underweight.
Participants reported that managing underweight was difficult, particularly in that some participants believed that it was harder to address underweight than overweight because they could not force underweight residents to eat. Although guidance is available for supporting people with learning disabilities and dysphagia to eat sufficiently (Harding & Wright, 2010), there does not appear to be guidance for supporting underweight adults with learning disabilities who are physically able to eat but are declining to do so.

Some participants described feeling responsible for managing this difficult area of underweight, and feeling judged that people may assume that it relates to poor care. Although the importance of no-blame cultures has been emphasised in the National Development Team for Inclusion’s (2010) guide for commissioning learning disabilities services, these support workers did describe feeling judged and concerned that people might assume that if residents were underweight they were poorly cared for. Although no research was identified on support staff feeling judged, Pelchat, Levert and Bourgeois-Guérin (2009) concluded that fathers of children with a disability may have felt that their caring strategies were judged as less effective than mothers’, causing uncertainty and a tendency to withdraw. A similar process may have been happening with participants, that feeling judged may have contributed to their uncertainty on how to manage underweight.

Certainly, although participants understood underweight as being potentially important and likely to have health consequences, it appeared to be overshadowed by a greater emphasis on overweight, which seemed to have been prioritised more within participants’ services and in society. This was demonstrated by participants describing
the increased attention on overweight within their services and in public health, and being more able to name health consequences of overweight. This may have related to participants’ experience of finding underweight more challenging to address than overweight.

The increased attention on overweight compared to underweight described by participants appears to mirror the current evidence base, that there is significantly more research on obesity than on underweight in adults with learning disabilities.

The lesser attention to underweight may have reduced participants’ confidence in talking about underweight. However, it should be noted that participants did express concerns about underweight and whilst it is acknowledged that this may have been encouraged by the research, some participants were able to identify possible health consequences of underweight. It appears that although participants may not have felt very confident about talking about underweight, they did realise that it might be a problem.

Participants reported that seeking guidance and working together was helpful in addressing underweight. Teamwork has been associated with quality of life for people with learning disabilities (Petry, Maes & Vlaskamp, 2007). Although Petry et al.’s study looked at people with profound learning disabilities, Mascha (2007) found that lack of teamwork and communication was considered a source of stress among support workers in a day centre working with adults with a range of severity of learning disability. Together, this suggests that teamwork is important for both staff morale (which has been linked to quality of care, Mascha) and client quality of life. This fits
with participants emphasising teamwork for themselves and for developing and following a plan to support residents.

**Implications and recommendations**

*For service users*

The finding that participants believed that underweight received less attention than overweight within their services and in health settings suggests that many underweight adults with learning disabilities may not be identified or receive comprehensive support.

The participants suggested that adults with learning disabilities may lack understanding around underweight. While it might be necessary to find further evidence to support this finding, it nevertheless suggests a possible need to help residents develop their understanding about underweight. This could include education about why bodies need food, what types and amounts of food are healthy and the consequences of not eating enough. This could be done in conjunction with education around overweight that is happening already (Jinks, Cotton & Rylance, 2010), as part of supporting healthy lifestyles, and integrated with teaching food preparation skills, which is considered a priority for people with learning disabilities (Lancioni & O’Reilly, 2002). It would be helpful to explore whether factors found to be effective in weight management interventions for obesity, such as those identified Spanos et al. (2013), could be used to design weight management interventions for underweight residents.
For staff/services

Participants’ uncertainty around managing underweight suggests that national practice guidelines, similar to those in place for obesity (Public Health England, 2016) could be useful. Participants identified a range of potentially helpful strategies, including establishing regular weighing, and responses for residents identified as underweight. Further research could establish the effectiveness of these strategies, and seek to identify others. Further research could also explore the possible reasons for underweight (including medical, psychological and environmental factors) suggested by participants which have not previously been identified, potentially leading to novel strategies.

Training for staff on the areas suggested for the guidelines above could be helpful. This could also include why underweight is important and how it could be missed, particularly if it appears that an increased emphasis on overweight may overshadow underweight.

The differences that participants identified between residents and the general population could be addressed by attempting to develop collaborative and mutual relationships. Cushing and Lewis (2002) outlined four shifts required in caregivers’ perceptions of people with learning disabilities and the goals of caregiving to support this, including seeing people with learning disabilities as the subject of their own life rather than as the object of care; recognising and accounting for differences in ability and power and creating conditions for trusting and open relationships.
For future research

The lack of good-quality studies into prevalence and factors associated with underweight in adults with learning disabilities suggests that further research is required to develop a better understanding and possibly a biopsychosocial model of underweight in adults with learning disabilities.

These findings suggest that further research is also required to understand how people with learning disabilities think about eating, weight and health, and whether this is different from the general population. It would be helpful to hear the perspectives of adults with learning disabilities about their beliefs and understanding of underweight. Hoole and Morgan’s (2011) research suggests that adults with learning disabilities value being involved in services, particularly around how they are supported. McCombens (2007) described how research itself can be undertaken collaboratively with adults with learning disabilities.

Observational studies could contribute to this, such as those used as part of nutritional status and risk assessments (Humphries, Traci & Seekin, 2009), exploring eating patterns and circumstances of underweight residents and how staff support them.

This research has investigated the perspectives of support workers of underweight in adults with learning disabilities. It would be interesting to explore how this compares with the views of others who are influential in supporting the wellbeing of adults with learning disabilities. This could include GPs, dietitians and family members of adults with learning disabilities as their perspectives have not been researched.
**Evaluation of the study**

This study investigated the experiences of a small sample of support staff recruited from three services within the same geographical location. Although this was appropriate to the research approach and methodology, it elicits limitations in the applicability of the findings outside of the sample. There were more female than male participants, although this might reflect a higher prevalence of female support staff. One participant (Sam) had less than the six months’ experience requested as they had not understood this requirement, however their data was considered in the context of their relatively short experience. Sam was one of four participants with fewer themes and quotations in the results section (along with Chris, Frankie and Ali) who the researcher experienced as having a lower level of confidence in talking about underweight and therefore struggled to engage fully in the interview. Attempts were made to support participants to feel comfortable by meeting them beforehand to explain the study, particularly around confidentiality, sharing the research topics and giving participants the option not to talk about topics should they feel uncomfortable. In future, it could be helpful to share the interview schedule with participants before the interview to help them feel more prepared. This might facilitate participants to feel more comfortable in sharing their perspectives when questions encourage them to elaborate on their views. It may also be that the uncertainty around underweight found in this study caused participants to feel uncomfortable about talking about it. This adds to the importance of encouraging staff to talk about underweight within services.

It is acknowledged that the voices of adults with learning disabilities were not present explicitly within this research because it was seeking to explore the views of support workers. It could have been helpful to involve adults with learning disabilities in the
study design and in monitoring the research process, which suggests an area in which future research could build on this study.

The novice status of the researcher may have had an impact on the quality of the research, for example prompting an over-reliance on the interview schedule. This was addressed by reading advice on conducting this type of research (Smith et al., 2009) and examples of similar research and by considering the four areas of quality outlined by Yardley (2000) throughout (Appendix M). Regular supervision with experienced supervisors throughout the process (including at all stages of the analysis), discussing the analysis with a peer experienced in qualitative research and practising the interview also helped to support the credibility and overcome some of the limitations identified.

In addition to these limitations, a significant strength of this study is in being the first to explore underweight in adults with learning disabilities as the primary focus. This research has led to implications for people working with adults with learning disabilities and the research required to ensure that services attend to underweight and intervene in an effective way.

**Conclusion**

This research explored the perceptions of support staff of underweight in adults with learning disabilities and found that participants revealed a sense of uncertainty about underweight, including holding different ideas about it. Participants understood underweight among residents as different from underweight in the general population and found it challenging to support underweight residents. Overall, as might be anticipated from the current lack of research into underweight in adults with learning
disabilities, the participants reported that supporting underweight residents was complex. This suggests the need for further research, particularly exploring the perspectives of adults with learning disabilities and other professionals, around their understanding of underweight. The development of an evidence base from which to develop national practice guidelines on identifying and responding to underweight among adults with learning disabilities may further support understanding, assessment and management of underweight in adults with learning disabilities.
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Appendix A: Journal JARID Author Guidelines

Crosscheck
The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

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/](http://authorservices.wiley.com/bauthor/) for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

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.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

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](http://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.

2.3 Clinical Trials
Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (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, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding
Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author’s conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.
The Journal of Applied Research in Intellectual Disabilities requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.
If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.
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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 (.rtf) 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.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at https://authorservices.wiley.com/statements/data-protection-policy.html.

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. Words in Tables, Table captions/legends, Figures and Figure captions/legends are excluded in the limit.

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.

**Running Title:** A short title of not more than fifty characters, including spaces, should be provided.

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

**Main Text:** All papers should have a structured abstract (maximum 150 words) as follows:

- Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables 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 l (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
APA - American Psychological Association
References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the APA FAQ. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

**Journal article**

**Example of reference with 2 to 7 authors**


**Example of reference with more than 7 authors**
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).


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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](http://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.

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Appendix B: Rationale for approach and methodology

Epistemology
A social constructionist perspective was adopted by this research due to its key principle that knowledge is sustained by social processes (Burr, 2003). This felt appropriate to the aim of this research in exploring individuals’ experiences and perceptions.

Qualitative approach
This study used a qualitative design and an inductive exploratory approach. The rationale for this was that little research has been conducted in this area, so a qualitative phase was felt to be required for an initial exploration that would allow themes to arise from the data and enable future, more focussed research.

Interpretative Phenomenological Analysis (IPA)
As a phenomenological and hermeneutic approach (Smith, Flowers & Larkin, 2009), IPA was identified as an appropriate way to support the exploration and interpretation of participants’ individual experiences and the meanings attributed to them. The broad nature of the aims of this research around understanding individuals’ perceptions meant that the idiographic nature of IPA was considered particularly appropriate. This supports the understanding of individual experiences and how they relate to shared experiences with other participants. The double hermeneutic approach acknowledges the influence of the researcher and their experiences in their interpretations and analysis (Willig, 2013). This can also be understood within the hermeneutic circle, whereby the meaning of words and sentences are understood within the different levels of context within which they are situated. It is also of note that IPA subscribes to social constructionism, understanding individuals’ experiences as enmeshed with their language and culture (Smith et al., 2009).

References:


Appendix C: Reflective statements

Reflection on the topic
I reflected on what had drawn me to this area of research, particularly on two underweight people with learning disabilities I had worked with in two different settings.

Firstly, as a support worker, I had worked with a young adult who had reduced her food intake and subsequently lost weight, leading her to be underweight. As support workers, we were unsure how best to support her and sought advice from different places. I recollect my colleagues having different understandings of the underweight and therefore how we might best support her. Her father had recently passed away unexpectedly and some support workers understood the underweight to relate to this, either that her strong emotional reaction had reduced her appetite, or that her not eating was a way of her communicating her sadness to us. We sought support in line with each of these perspectives, from a dietitian and a psychologist respectively. I remember that there was a wait to receive this professional support and that in the meantime, we were attempting to support the client as best we could, whilst feeling quite stuck and powerless.

My second experience was as an occupational therapist in an eating disorders service. A young woman with learning disabilities was referred to the daypatient programme with possible anorexia nervosa. I met this lady and her mother and some of my colleagues to discuss what support might be most appropriate. We concluded that this would not be within the day programme as she was unable to commit to this alongside the support she was receiving from other services such as addictions and forensic services. This experience led me to appreciate the complexity of underweight in people with learning disabilities. I also realised that our inpatient and daypatient eating disorders service was not very accessible to people with learning disabilities, for example realising that much of the group programme was talking-based and would have required adaptation to support her to engage with it fully.

These two experiences led me to be interested in the topic of underweight in adults with learning disabilities, with a sense that it is something not fully understood or addressed, a desire to understand this better and a hope that this might somehow help to improve the experiences of people with learning disabilities who are underweight.

I discussed my experiences with my two supervisors and we thought together about how this related to the available research on this area and therefore what an appropriate research topic and question might be. This helped to ensure that the research was not only based on my experiences and perspectives but was supported by the research evidence available (and also by the gap in the literature that suggested further exploration was warranted).

In designing the interview schedule, I discussed possible questions with both my supervisors, with colleagues who had worked as support workers in learning disabilities services and with MDT members currently working in learning disabilities services (including the external consultant to the project). This helped to broaden the extent of experiences that the interview questions were based on, seeking alternative perspectives on how support workers could be supported to engage in the topic, rather than basing this only on my experiences and perspectives. I also practised the interview with a colleague who had experience as a support worker to see how the interview schedule worked in practice.

Reflection on weight
I understand weight from a biopsychosocial perspective, that it is influenced by a multitude of different factors, including biological, psychological and social factors. I am aware that weight is something that can change and that people’s experiences of their weight and shape may also change over time. I have experienced the possible impact of weight on people’s identity, that people may identify as a larger or smaller person and that people can be more or less satisfied with their weight. I reflected on how unhappiness with weight may have an impact on how people feel about themselves and the actions they might take to attempt to change their weight, such as changing their diet or exercise routine or joining with other people with similar aims, such as in a weight loss group.
I reflected on the fact that I am a White British female in my early 30s and the role of my own experiences in shaping my views around weight, including how it has been talked about in my family and with friends, peers and colleagues. I also reflected on my experiences of how weight has been portrayed in wider society, from the use of underweight models in magazines or actresses in films (and how such people’s weight has been scrutinised in the media) to campaigns to promote more acceptance of a wider range of body shapes and sizes.

I reflected on the fact that I have worked in an eating disorders service, primarily with people who have anorexia nervosa, where body weight and shape was a priority and something that we discussed daily, from psychological, medical and occupational perspectives (particularly as I was working as an occupational therapist in that setting).

Reflections prior to the interviews
I reflected on the interview schedule, considering my own previous experiences of being a support worker and how I might have responded to the questions when I worked as a support worker. I discussed the potential questions with both Therapy Leads currently working in learning disabilities services and PsychD colleagues who had previously worked in learning disabilities services. We reflected on their experiences and how they felt they might have responded to the proposed questions, which prompted me to reflect further on my experiences and possible responses.

I reflected on the fact that my views on weight may have varied from those of my participants, including reflecting on the fact that my participants might be different ages, gender and ethnicity from myself, all of which have been found to influence views on weight. I reflected on how participants might have perceived my own weight and any assumptions they might have had based on that.

I reflected on views and experiences that participants may hold about their own weight and how this may influence their responses to questions and also their experience of the interview. I was aware that I was unlikely to know the nature of these views and experiences as the questions did not ask about these, unless the participants chose to disclose these as part of their other answers. However, I was aware that I needed to maintain an awareness of the potentially sensitive nature of the topics for participants.

I reflected on the fact that most of the participants were female and wondered if this related to weight being something that may be discussed more commonly by women (and so whether female support workers were more willing to participate in this research on underweight), or whether it related to the fact that more support workers are female than male.

Reflections around data collection
During the interviews, I was mindful to attend to what each participant was saying about their own experience, using the interview schedule and prompts to explore participants’ meaning further in relation to the interview topic. Asking these questions and adopting a curious approach supported me to explore participants’ perspectives and meanings rather than making assumptions based on my own experiences.

After completing each interview, I wrote notes on my experience of them, which I referred back to when I started the analysis. This helped me to be aware of what my initial reactions to each interview had been so that I could bear this in mind as I analysed each transcript. Being aware of my initial reactions supported me to ensure that I sought evidence for anything that fit with these experiences (rather than just accepting assumptions). This awareness, alongside close contact with my supervisors, also helped me to ensure that I sought alternative perspectives throughout the analysis process.

Reflections around data analysis
During the analysis process I made notes of my thoughts and feelings at the different stages.

I noticed that the sense of uncertainty around underweight expressed in the first superordinate theme was in keeping with my experiences as a support worker working with a resident with learning disabilities who was underweight without a clear understanding of what had caused the underweight. I ensured that each theme was clearly supported by evidence from a number of interview transcripts. Close contact and discussions with my supervisors throughout the analysis process also helped to
ensure that I was not unduly swayed by own experiences and that I was also seeking different perspectives and themes within the data that did not fit my own experiences. My supervisors encouraged me to interrogate the data to support me to reach the essence and meaning of what participants were saying and ensure that the themes were well supported with evidence. I also discussed my analysis with a peer with experience of qualitative analysis who supported me to justify the development of the themes with evidence from the interview transcripts.

I could relate to the increased discussion of overweight compared to underweight but was surprised at how this appeared to translate to overweight being treated more urgently as I had experienced underweight being taken seriously as a support worker, which didn’t always seem to be the case for the participants.

I found that I had mixed feelings around the theme of adults with learning disabilities being different from the mainstream population. This was something I had some awareness of people feeling as a support worker but perhaps less so than the participants. Most of my experience as a support worker was in a residential college for young adults with learning disabilities where the emphasis was on supporting people to develop skills to enable them to live as independent a life as possible. That meant that there was an emphasis on working with people’s potential and a belief that we should be maximising this. I wondered whether participants working in more longer-term settings than I had, or with older service users had different experiences and expectations of service users, particularly without the educational college nature of my experience.

I could identify with some of the challenges of supporting underweight adults with learning disabilities that participants emphasised, particularly around not being able to force people to eat, and the importance of working together and trying different things to identify strategies that worked for that individual. I was somewhat surprised about people’s concerns about judgements and assumptions as this was not something that I had experienced. I wondered if this was related to the impact of the Winterbourne View and other similar scandals that were only just being identified when I worked as a support worker.

I was aware that my experiences of working in eating disorders services, particularly with people with anorexia nervosa, may have influenced my views on underweight and predisposed me to see underweight in the context of possible eating disorders. I noticed that this was different from the participants, none of whom mentioned eating disorders in the context of residents with learning disabilities, although some mentioned it as a possible cause of underweight in the general population. This supported me to identify the many and complex understandings of underweight and facilitated the analysis to focus on the participants’ experiences, beyond my own perspective.

Excerpts from reflective log
16th May 2017: I have worked in both learning disabilities and eating disorders services. In the learning disabilities service, I worked with someone who stopped eating, apparently for psychological reasons (related to distress). Staff were unsure how best to support her and it caused anxiety among the team in addition to the distress experienced by the service user. In the eating disorders service, someone who had a learning disability and appeared to have anorexia was referred. I became aware of possible barriers to accessing eating disorders services that people with learning disabilities may face. I am interested in both learning disabilities and eating disorders, and there appears to be a gap, both in understanding and addressing this area.

23rd November 2018
The analysis process is taking so long that I’m wondering whether I’m doing it wrong and my themes are too generic. Parts of the interviews don’t feel very relevant but they still help me to understand the participant’s experience. I’m slightly worried that my data isn’t rich enough, or maybe it’s my interpretation that is struggling to identify the rich meanings behind the data.

25th November 2018
I’m aware of the language used by participants and how this relates to my experiences and values, for example one participant referring to the service users as ‘them’. I found myself copying this language of “them” once in my notes, which made me feel uncomfortable and not want to do this again. I’m struggling with some of the initial themes that feel that they contradict slightly with my values and the
impact this has on decisions such as naming themes, for example feeling more comfortable when people with learning disabilities are viewed as different rather than ‘inferior’.

15th January 2019
I’m worried that my themes are too descriptive and not analytical enough. I don’t feel very confident on how to move beyond this and find the interesting ‘essence’ and meaning of the themes. I know that this is all new to me but the description and examples in the Smith book make it look so easy, which is very different from my experience of doing it.

29th January 2019
There seem to be lots of different ways that I could connect and interpret the data. Part of me wants to know what the ‘best’ way to do this would be but I know that there is no ‘right’ way in qualitative research. I’m aware that I’m new to this type of research and want to make sure that I’m following the steps of the analysis process in a way that will support an effective analysis and interpretation of the data.

4th February 2019
How do the categories and themes fit my experiences and values?
Do I see adults with learning disabilities as fundamentally different from the general population? I’d like to think not as it feels at odds with my values that everyone is equal and an individual with their own unique experiences and needs.

Do I see adults with learning disabilities as challenging to work with? I’m aware that I really enjoy working with adults with learning disabilities (and can see myself going into this area as a qualified psychologist) and that I can find aspects of the work challenging. Is this due to something about learning disabilities though, or something more specific to those situations? I think it can be both, challenging and rewarding.

Am I uncertain about managing underweight in adults with learning disabilities? I certainly was as a support worker and an occupational therapist. I was uncertain about how these clients could be supported most effectively and spent a lot of time discussing this with the individuals and my colleagues.

How would I feel if I were a support worker, grappling responsibilities/duty of care with uncertainty/lack of confidence/training? I think I would also have found many of the situations described by participants as challenging. I therefore want my analysis to be balanced, acknowledging what they are doing in the face of challenges rather than criticising/assuming I could do ‘better’.

5th February 2019
I’m worried about losing some of the richness and the detail of the data. There is so much that is interesting and it’s hard to decide what to prioritise. I’m trying to bear the initial research question and the problem that the research is trying to address in mind, to help me decide what is most relevant and useful in answering the question and problem.
Appendix D: Recruitment email to service managers

Subject: Study on underweight in adults with learning disabilities – recruitment of support staff as participants

ATTACHMENTS:
- Participant information sheet.
- Consent form.

Dear [name],

I hope you don’t mind me contacting you. I have received your contact details from [Therapy Lead name] who I understand has spoken to you about the research study I am conducting.

I am a Trainee Clinical Psychologist based at the University of Surrey and employed by Surrey and Borders Partnership NHS Foundation Trust. I am conducting a research project exploring how support staff understand, assess and manage underweight among adults with learning disabilities that they support. This study is being supervised by Dr Nan Holmes and Dr Kate Gleeson. It has received ethical approval from the University of Surrey.

Previous research suggests that adults with learning disabilities are more likely to be either obese or underweight than adults without learning disabilities. The World Health Organisation tells us that both obesity and underweight are associated with significant health concerns.

Many studies have explored obesity in adults with learning disabilities and this has led to interventions to address obesity. There are fewer studies of underweight in adults with learning disabilities but one such study associated underweight with certain behaviours that may have functions for that individual. These functions are currently unknown, but this suggests that further exploration of underweight in adults with learning disabilities would be helpful.

No research has been reported on how support staff perceive and respond to underweight in adults with learning disabilities. The purpose of this study is to explore this.

I would like to recruit support staff who are working with adults with learning disabilities to participate in my research through an individual interview on the above topics. The interview will last 30-60 minutes and will take place at a mutually convenient time in a confidential workplace environment, ideally within the service that the support staff work in. Before consenting to participate in the interview, participants will have received a participant information sheet (as attached) and will have an opportunity to ask questions or request further information.

Participants will be asked to complete a very short questionnaire about themselves before commencing the interview. Participants will be asked to talk about their work with adults with learning disabilities generally as we will not have consent to discuss individual service users in detail. Anonymous quotes from the interviews will be used in the write-up of the research. Every effort will be made to remove any identifiable information from anything that is written up from this research.

The interviews will be recorded on an audio recording device and recordings will then be transferred onto a password-protected encrypted USB stick on site. The interviews will be transcribed and transcriptions will also be stored on a password-protected encrypted USB stick. The interviews will be analysed for themes arising from them.

We hope that the results will be published in a relevant journal. We will also write a summary of the results that we will send to the services that have participated in the study to be shared with participants and managers. The results may also be presented at meetings, support groups or conferences, as appropriate.

Please see the participant information sheet and consent form attached for further information about the study.
Please email me on n.godfrey@surrey.ac.uk by [date – 2 weeks from sending] to let me know whether or not you are willing for support staff working in your service to participate in this study. If you have any questions, please do not hesitate to contact me. I am also very happy to discuss the study over the telephone or in person if you would like further information.

I look forward to hearing from you.

Yours sincerely,

Nicky Godfrey
Trainee Clinical Psychologist
Appendix E: Participant Information Sheet

Participant Information Sheet
[Version 5, 13/06/18]

Exploring Support Staff's Perceptions of Underweight in Adult Service Users with Learning Disabilities: A Qualitative Study

Support Staff

Introduction
We would like to invite you to take part in a research project. Before you decide you need to understand why the research is being done and what it will involve for you. Please take the time to read the following information carefully and ask questions about anything you do not understand. You can talk to others about the study if you wish.

What is this study about?
This study aims to explore how support staff working with adults with learning disabilities understand, assess and manage underweight in the people they support.

Why have I been invited to take part in the study?
You have been invited to take part in this study because you are a member of support staff working in a service that is participating in this study.

To be eligible to take part in the study, you must meet the following criteria:
- Currently employed as a support worker with adults (aged 18 years and over) with learning disabilities.
- Have 10 or more hours of 1:1 contact per week with adults with learning disabilities.
- Have at least six months of direct support experience with this client group.
- Have responsibility for supporting service users to maintain good physical and mental health.
- Good understanding of and ability to express spoken English.

About 10 participants will take part in this study.

Do I have to take part?
No, taking part in this study is entirely up to you. There will be no consequences for you if you say no. To help you decide whether or not to take part, you can talk it over with friends, family, colleagues, etc. You can also contact the researcher for further information and I will be happy to answer any questions. These contact details are at the end.

Even if you agree to take part, you can choose not to answer all of the questions in the interview and you can also stop the interview at any time without giving a reason. If you change your mind about participating after the interview, you have the right to withdraw the information that you give me by emailing me at any time up until 21st September 2018. That is when I shall start analysing the data from everyone who has participated.

What will my involvement require?
If you agree to take part, you will be asked to sign a consent form. You will be given this information sheet to keep and a copy of your signed consent form. The research will last approximately 18 months but your involvement would only be for one interview and a very short questionnaire completed before the interview.

**What will I have to do?**
You will participate in one interview of up to an hour in length at a convenient time for you and in a confidential workplace environment, which could be your place of work. The interview will be recorded. You will be asked to complete a very short questionnaire before the interview. During the interview, please speak about your experience of supporting adults with learning disabilities in general. We do not have consent from individual adults you support to be discussed in detail.

**Will my taking part in the study be kept confidential?**
In most circumstances, your details will be held in confidence and we will follow ethical and legal practice in relation to all study procedures. Personal data (your name, contact details, audio recordings etc) will be handled in accordance with the Data Protection Regulations so that unauthorised individuals will not have access to them.

In certain exceptional circumstances where you or others may be at significant risk of harm, the researcher may need to report this to an appropriate authority, in accordance with the Data Protection Regulations. This would usually be discussed with you first. For example, if the researcher becomes concerned about a potential safeguarding issue, they will follow up these concerns with the local safeguarding team and may have to break confidentiality to do so, as appropriate.

Further examples of those exceptional circumstances when confidential information may have to be disclosed are:
- The researcher believes you are at serious risk of harm, either from yourself or others.
- The researcher suspects a child may be at risk of harm.
- You pose a serious risk of harm to, or threaten or abuse others.
- As a statutory requirement e.g. reporting certain infectious diseases.
- Under a court order requiring the University to divulge information.
- We are passed information relating to an act of terrorism.

**What will happen to data that I provide?**
- Interviews will be recorded on an audio device and then transferred onto a password-protected encrypted USB stick through a laptop at the interview site. They will subsequently be uploaded to a secure university drive.
- Once recordings are on the password-protected encrypted USB stick, they will be deleted from the audio recording device.
- The password-protected encrypted USB stick will be stored securely.
- You will be allocated a unique code known only to the researcher and supervisors, which will only be used if you wish to withdraw from the research.
- Written transcriptions of the recordings will be stored on a password-protected encrypted USB stick and on a secure university drive.
- Once the study has been completed, paper transcriptions will be stored in a locked secure location by the supervisors. Electronic transcriptions will be saved on a secure university computer drive.
- Your interview will be listened to by the researcher. It may also be listened to by transcribers and supervisors. If anyone else becomes involved due to safeguarding issues being raised, they may also listen to the interview.
- Transcripts will be seen by the researcher, transcribers and supervisors. They may also be seen by any other researchers who become involved in the project and examiners. If anyone else becomes involved due to safeguarding issues being raised, they may also see the transcripts.
- Anonymous quotes from your interview may be used when the research is written up. We will make every effort to remove any identifiable information from anything that is written up from this research.
- Questionnaire answers will be scanned and saved on the password-protected encrypted USB stick and on a secure university drive.

Your data will be accessed, processed and securely destroyed by the researcher and supervisors. In order to check that this research is carried out in line with the law and good practice, monitoring and auditing can be carried out by independent authorised individuals. Data collected during the study may be looked at by authorised individuals from the University of Surrey, from regulatory authorities, where it is relevant to your taking part in this research. All will have a duty of confidentiality to you as a participant and we will do our best to meet this duty. We will anonymise any documents or records that are sent from the University of Surrey, so that you cannot be identified from them.

The data you provide will be anonymised and this and your personal data will be stored securely. You will not be identified in any reports/publications resulting from this research and those reading them will not know who has participated in it. We will use anonymous quotations in reports.

Research data are stored securely for at least 10 years following from the completion of the degree, the date of any publication based on the data or their last access. Project data (e.g. your consent form) will be stored securely for at least 6 years in line with the University of Surrey policies. Personal data will be handled in accordance with the Data Protection Regulations.

With your consent, to make the most of your participation and support efficient advancements in science, any anonymised data may be used for future research. We cannot tell you at the moment what this research will involve but we can assure you that all appropriate legal, ethical and other approvals will be in place. For practical reasons your consent will not be sought again unless you tell us that you want us to do this.

As a publicly-funded organisation, we have to ensure when we use identifiable personal information from people who have agreed to take part in research, this data is processed fairly and lawfully and is done so on the basis of public interest. This means that when you agree to take part in this research study, we will use your data in the ways needed to conduct and analyse the research study.

All project data related to the administration of the project, (e.g. consent form) will be held for at least 6 years and all research data for at least 10 years in accordance with University policy. Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you decide to withdraw your data from the study, we may not be able to do so. We will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.
You can find out more about how we use your information https://www.surrey.ac.uk/information-management/data-protection and/or by contacting dataprotection@surrey.ac.uk

**Who is Handling My Data?**
The University of Surrey, as the sponsor, will act as the 'Data Controller' for this study. We will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly. This information will include your name/workplace, which is regarded as 'personal data' and your ethnic origin, which is regarded as a 'special category personal data'. We will use this information as explained in the ‘What will happen to the data I provide?’ section above.

What if I want to complain about the way data is handled?
If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer Mr James Newby who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (https://ico.org.uk/).

For contact details of the University of Surrey's Data Protection Officer please visit: https://www.surrey.ac.uk/information-management/data-protection

**What are the possible disadvantages or risks of taking part?**
It may be upsetting to think about problems with weight and eating, for the adults you support, yourself or anyone else that you know. It can also be difficult to think about how you work and if there is anything you could do differently.

**What are the possible benefits of taking part?**
This study will let you think about how you work with people who are underweight and if there is anything that you could do differently in future. This research may help to influence future training and how staff are supported in this area. Changes to services are based on the findings of research studies. Your input helps us to discover what is working and what needs improving.

**What happens when the research study stops?**
The results of the study will hopefully be published in a relevant journal. The results will also be given to the services that have participated in the study through a summary written for both participants and service managers. The results may also be presented at meetings, support groups or conferences, as appropriate.

**What if there is a problem?**
If the interviews bring up difficult feelings, please speak to your manager for advice on specific sources of support. If you would like support around any difficulties that you have or are experiencing around eating or weight, you can receive further information and support from the charity BEAT (the UK eating disorders charity - https://www.beateatingdisorders.org.uk). If you are concerned about weight or eating difficulties with someone you support, please seek advice from the individuals’ GP.

If you share information that leads to sufficient concern about your safety or the safety of others, the researcher will discuss these concerns with their supervisors. They may have to break confidentiality to do this, as is most appropriate to the situation. They
have the same responsibility as any other NHS employee to safeguard people and local multi-agency safeguarding procedures will be followed if necessary.

Any complaint or concern about any aspect of the way you have been dealt with during the study will be addressed; please contact the supervisors Dr Nan Holmes (01483 689433, n.holmes@surrey.ac.uk) or Dr Kate Gleeson (01483 683995, kate.gleeson@surrey.ac.uk) in the first instance. You may also contact the head of the Clinical Psychology course who is independent of the research team – Ms Mary John (01483 689441, m.john@surrey.ac.uk). If you remain unhappy you can file a complaint using the University of Surrey complaints procedure.

The University has in force the relevant insurance policies which apply to this study. If you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should follow the instructions given above.

If you are harmed due to someone’s negligence, then you may have grounds for legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during this study then you should follow the instructions above.

**Full contact details of researcher and supervisors**
Nicky Godfrey (Researcher) – n.godfrey@surrey.ac.uk
Dr Nan Holmes (Supervisor) – n.holmes@surrey.ac.uk
Dr Kate Gleeson (Supervisor) – kate.gleeson@surrey.ac.uk

**Who is organising and funding the research?**
This research is organised by the University of Surrey.

**Who has reviewed the project?**
*This research has been looked at by an independent group of people, called an Ethics Committee, to protect your interests. This study has been reviewed by and received a favourable ethical opinion from the University of Surrey Faculty of Health and Medical Sciences Ethics Committee.*

**Thank you for taking the time to read this Information Sheet.**
Appendix F: Consent form

Consent Form
[version 6, 13/06/18]

Exploring Support Staff’s Perceptions of Underweight in Adult Service Users with Learning Disabilities: A Qualitative Study
[1334-PSY-17]

Please initial each box

- I have read and understood the participant information sheet provided (version 5, date 13/06/18). I have been given a full explanation by the researchers of the nature, purpose, location and likely duration of the study, and of what I will be expected to do.

- I have been advised about any disadvantages/risks to my well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given.

- I agree to comply with the requirements of the study as outlined to me to the best of my abilities.

- I agree for my anonymised data to be used for this study or any future research that will have received all relevant legal, professional and ethical approvals.

- I agree for my special category data (ethnic origin) to be collected for the purposes stated in the information sheet.

- I give consent for the interview to be audio recorded.

- I confirm that I have been told that the interview will be listened to by the researcher. It may also be listened to by transcribers and supervisors. If anyone else becomes involved due to safeguarding issues being raised, they may also listen to the interview. I have been told that transcripts will be seen by the researcher, transcribers and supervisors. They may also be seen by any other researchers who become involved in the project and examiners. If anyone else becomes involved due to safeguarding issues being raised, they may also see the transcripts.

- I confirm that I have been informed about confidentiality procedures, that my data will be kept confidential in most circumstances. I have been informed that if I share information that leads to sufficient concern about my safety or the safety of others, these concerns will be shared with the researcher’s supervisors. Safeguarding procedures may then be started, if this is considered appropriate. The researcher may have to break confidentiality to do this, as is most appropriate to the situation.

- I give consent for anonymous verbatim quotation being used in reports.
• I understand that all project data (related to the administration of the project, e.g. my consent form) will be held for at least 6 years and all research data for at least 10 years in accordance with University policy.

• I understand that my personal data is held and processed in the strictest confidence, and in accordance with the Data Protection Regulations.

• I agree for the researchers to contact me to provide me with a summary of the study results.

• I agree for the researchers to contact me about future studies.

• I understand that all data collected during the study may be looked at for monitoring and auditing purposes by authorised individuals from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

• I understand that I am free withdraw from this study at any time up until (21st September 2018), when the data analysis will start. I know that I can do this without needing to justify my decision, without prejudice and without my legal rights and employment being affected.

• I understand that I can request to withdraw the information that I give by emailing the researcher at any time until (21st September 2018), when the data analysis will start, and that following my request all personal data and data already collected from me will be destroyed.

• I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation.

Name of participant (BLOCK CAPITALS) ......................................................
Signed ......................................................
Date ......................................................

Name of researcher taking consent (BLOCK CAPITALS) ......................................................
Signed ......................................................
Date ......................................................
Appendix G: Interview Schedule

Exploring Support Staff’s Perceptions of Underweight in Adult Service Users with Learning Disabilities: A Qualitative Study
(Notes in italics are aide memoire for interviewer.)

Broad interview topics
- Role as support staff.
- Weight and health.
- Weight issues and learning disabilities.
- Underweight and learning disabilities.

Consent to record
- Do you remember that in the information sheet, I mentioned that the interviews would be recorded?
- Are you ok for me to start the recorder now? We’re not starting the interview questions just yet, but it’s helpful to record the consent process, that is me explaining what’s going to happen and to check that’s all ok with you before we start. Does that make sense? Is that ok?
- I’ll also be making notes as we go along too if that’s ok?

START RECORDING

Consent for interview
- On the information sheet, it explained that this interview would be about your experiences as a support worker of adults with learning disabilities, particularly focussing on your experience of supporting clients/service users who are underweight.
- Are you still willing to talk about these things?
- The information sheet also explained that the interview would be recorded.
- Are you still willing for the interview to be recorded?
- It explained that all the data would be confidential, apart from in exceptional circumstances, such as if we were to believe that you or someone you support were at significant risk of harm.
- Does that make sense and sound ok?
- It explained what will happen to the recording and the information you provide.
- Would you like me to go through that or explain anything further?

- The interview would be recorded on this recording device and then transferred to a password-protected USB stick and deleted from the recording device whilst I am here at the care home. I will transcribe the interview (write out what we both say word for word) and the written transcriptions will also be kept securely. Anonymous quotes from the interview may be used when I write up of the research as my supervisors and I hope to publish an article about it.

- Based on all this, are you happy to consent to go ahead with the interview?

- Before we do that, I’ll explain what the interview is likely to look like.

Introduction
Thank you for agreeing to participate in this research. We are looking at underweight in adults with learning disabilities. In this interview, we will initially be discussing the links between weight and health. We will then be discussing your role in supporting service users who are underweight. We will move on to discuss weight issues in general and then underweight and adults with learning disabilities.

So, here are the topics that the interview will cover (show on separate piece of paper):
- Role as support staff.
- Weight and health.
- Weight issues and learning disabilities.
- Underweight and learning disabilities.
Are there any of these topics (or parts of the topics) that you would not like to discuss during the interview?

It might be helpful for you to bear in mind individual clients that you are supporting or have supported in the past, so that you can answer the questions based on these experiences. However, I do not need to know details about individual clients.

As I have explained, this interview is being recorded. Have you got any questions before we start?

Possible interview questions:
1) Before we start talking about learning disabilities specifically, I’d like you to tell me a bit about your views on weight generally.
   In general terms, what does the term overweight mean to you? How would you describe it?
   In general terms, what does the term underweight mean to you? How would you describe it?
   (Prompt - Include thoughts and feelings about overweight and underweight.)
   (Consider possible beliefs/values about weight.)

2) What do you think about the relationship between weight and health?
   (Prompt - Identify thoughts/feelings around this, and anything they do as a response.)

3) Now, moving on to talk about your work here. As we haven’t met before, I’d like you to tell me a bit about your job – what do you do here?
   (Prompt - Discuss how much contact with residents/service users/clients and what they do with them).
   (Prompt - What other support do they offer?)
   (Consider relevance to underweight?)
   (What do they call service users – residents/clients/service users/patients?)

4) What is your role in supporting service users’ health and wellbeing?
   (Prompt - Discuss weight.)
   (Prompt - Include discussion of who helps them in this and how.)
   (Consider relevance to weight/underweight.)

5) What is your experience of weight in relation to the people you support? How much do you think about it?
   (Prompt - Include overweight and underweight.)
   (Prompt - Include how they feel about weight among people with learning disabilities.)
   (Prompt - Include what they might do.)

6) Have you ever noticed that someone you have supported is underweight?
   (Prompt – What do you notice when someone you are supporting is underweight?)
   (Prompt – How would you recognise/know if someone is underweight?)
   (Prompt – Examples of how might notice e.g. weighing/weight from GP.)
   (Prompt – Do you discuss weight with your colleagues?)
   (Prompt – How common or unusual is it for someone you are supporting to be underweight?)

7) What is your experience of supporting service users who are underweight?
   (Prompt – What do you do when someone you are supporting is underweight?)
   (Prompt - Consider thoughts and feelings around this – what is it like?)
   (Prompt - Consider difficulties in supporting, managing and getting help for services users and what has been helpful (in general and also what has been helpful to do)).

8) Based on your experience, what are your thoughts about factors that might cause adults with learning disabilities to be underweight?
   (Prompt - Consider anything they might do as a result of this.)

9) Do you think there are any differences in underweight for adults with learning disabilities compared to adults without learning disabilities or is it the same?
   (Prompt – How is it different? How is it the same?)
   (Prompt – Consider differences/similarities in causes/factors in underweight.)
(Prompt – Consider differences/similarities in managing/supporting underweight.)
(Prompt - Consider how this might affect what they do as a result.)

- If this information has not come up during the interview, ask the following:
  - How long have you been working in your current role?
  - What was your path into your role?
    (Prompt - include previous relevant work/education history)
- Is there anything you would like to add to what you have said in relation to how you understand, assess and/or manage underweight, or any questions you would like to go back to?

Closing Comments
Thank you very much for participating in this interview – I’m really looking forward to analysing the data. Have you got any questions before we finish?

Would you like to know anything else about the interview or the study?

If you have been affected by anything we have talked about and would like some support or to discuss this further, please [insert instructions from manager here]. If you are worried about anything related to your work in this area, either currently or previously, please speak to your manager.

Thank you again for participating.
Appendix H: Broad interview topics

- Role as support staff.
- Weight and health.
- Weight issues and learning disabilities.
- Underweight and learning disabilities.
## Appendix I: Demographic questionnaire

### What is your gender?
- Male
- Female
- Prefer not to say

### Which age range do you fall into?
- 18-25
- 26-35
- 36-45
- 46-55
- 56-65
- Over 65
- Prefer not to say

### What is your ethnic origin?

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<td>Irish</td>
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<td>Gypsy or Irish Traveller</td>
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<td>White and Black African</td>
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<tr>
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<tr>
<td>Any other ethnic group (please state)</td>
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</table>

| Prefer not to say                         | □                    |

(Questions taken from the 2011 UK Census.)
| URN number and Trainee Name: | Nicola Godfrey 6455603 |
| University Supervisor: | Nan Holmes, Kate Gleeson |
| Decision of RGC | Proceed with considerations |
| Project Title: | Exploring Support Staff’s Perceptions of Underweight in Adult Service Users with Learning Disabilities: A Qualitative Study |
| Overall comment | The proposal is basically sound but there are some considerations that you will need to discuss and clarify in supervision. |
| Considerations to be addressed. | There is one or more consideration to be addressed before you proceed with the project that must be discussed with your course team supervisor and resolved before you proceed. |

1. Is IPA an appropriate method to answer the research question?  
   *We chose IPA as we wanted to understand individuals' experiences in depth because it is such an under-researched area, rather than necessarily trying to identify themes across a range of individuals.*

2. Is 90 minutes too much of a busy care workers time to take  
   *I had wondered this, and someone else had suggested that 30-60 minutes might be more realistic. However, the Therapy Leads helpfully suggested that the interview questions may need to be made more simple and specific, and that some more basic questions may need to be added (e.g. a first question on ‘What is your understanding of the relationship between weight and health?’, rather than going straight into asking what their perspective/opinion is). They also suggested that I'm likely to need to use most of the prompts as individual questions, which may take more time. I'm planning to ask some trainees who have previously worked as support workers in learning disabilities to look at the questions prior to undertaking pilot interviews.*
| 3. | Ensure the interview guide is designed in order to elicit ‘depth’ in responses. I think this will be a slightly tricky balance, between making questions accessible to the participants and ensuring this depth. The Therapy Leads commented that some of the concepts are quite complex, but felt that it should be manageable with some suitably simple questions. Again, hopefully the trainees who have previously worked as support workers and the pilot interviews will help us to review the questions and depth of responses the questions are likely to elicit. I've had a quick look at the questions and made a few amendments (as attached), incorporating some of the suggestions and Therapy Leads and then including more ‘why’ questions as prompts for more depth, to encourage participants to express the reasons behind their answers. |
| 4. | |
| 5. | |

Chair of RGC signature: ____________________________ Date: 10.7.2017
Appendix K: Faculty of Health and Medical Sciences Ethical Approval

Chair's Action

Proposal Ref: 1334-PSY-17

Names of Student/Trainee: NICKY GODFREY

Title of Project: Exploring Support Staff’s Perceptions of Underweight in Adult Service Users with Learning Disabilities: A Qualitative Study

Supervisors: Dr Nan Holmes, Dr Kate Gleeson

Date of submission: 27th November 2017

The above Research Project has been submitted to the Faculty of Health and Medical Sciences Ethics Committee and has received a favourable ethical opinion on the basis described in the protocol and supporting documentation.

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

Ethics Application Form
Detailed protocol for the project
Participant Information sheet
Recruitment email
Consent Form
Risk Assessment (If appropriate)
Insurance Documentation (If appropriate)

All documentation from this project should be retained by the student/trainee in case they are notified and asked to submit their dissertation for an audit.

Signed and Dated: 09/01/2018
Professor Bertram Opitz
Chair, Ethics Committee

Please note:
If there are any significant changes to your proposal which require further scrutiny, please contact the Faculty of Health and Medical Sciences Ethics Committee before proceeding with your Project.
Appendix L: Ethical considerations

Weight can be a sensitive topic and may have led participants to reflect on their own or others’ weight as well as the weight of the service users they are supporting. Participants were advised of the area being researched at the information meetings and were provided with a list of broad topics before the interview started. They were asked whether there were any of these topics that they would not feel comfortable to discuss. None of the participants requested not to discuss any of the topics. Participants were also advised of their right to withdraw, on both the participant information sheet and the consent form they all signed. One participant requested to withdraw from the study prior to the interview. These steps were designed to support participants to feel at ease during the interview. At the end of the interview, participants were informed of sources of support should they feel concerned about eating or weight difficulties of their own or of someone they know. This was mostly through occupational health, as advised by the service managers.

It was acknowledged that discussing the practice of support staff could also be a sensitive topic, with the potential for participants to feel uncomfortable if they felt judged as if they should be doing something that they are not, or should have done something in the past that they did not. Participants were advised on the participant information sheet and verbally that they should speak to their manager if this was the case.

There was a risk that discussions around practice and managing weight may have elicited safeguarding concerns. The information sheet and consent form stated explicitly that any information disclosed by the participant that was deemed to constitute a safeguarding issue would be reported by the researcher in line with the local multi-agency safeguarding procedures, which may have required confidentiality to be broken. This was also explained verbally at the start of each interview.

The interview transcripts were anonymised by the removal of any names of staff members, service users, services or local areas. The data was stored and handled in line with data protection regulations and GDPR.
Appendix M: Consideration of quality issues

The quality and validity of this study were considered according to Yardley’s (2000) criteria and the guidance in Smith et al. (2009) on how to address these in IPA research.

Sensitivity to context

There were different levels and areas of context to be considered in this study. A review of the literature previously conducted in this area revealed firstly that little research has been conducted but also allowed consideration of how to support this research to build on what has been done previously.

It was also necessary to build relationships with services and staff and appreciate the contexts that they were working in, in order to engage staff with the rationale of the research and hopefully enable them to consider it relevant to their current and future work. Building a relationship with each participant that was sensitive to their context also supported the interview process as participants hopefully felt comfortable to discuss their practice and also weight, both of which could be sensitive topics.

Paying attention to participants’ contexts also supported the interpretation of the interview data, understanding how the interviews developed and unfolded. Using quotes from interviews demonstrates how the findings came from the data and the contexts and experiences of participants.

It was also important to pay attention to different aspects of my own context. I acknowledged that I was a novice researcher and therefore accessed appropriate support from my supervisors throughout the research process. I also completed a pilot interview with a colleague to practise the interview before interviewing any participants. I kept a reflective log and reflected on different aspects of my own diversity. I acknowledged that I was a Trainee Clinical Psychologist and reflected on possible power issues around this and what it might mean to participants, including assumptions they might make based on that. I told participants that I had worked as a support worker in learning disabilities previously and hoped that this might help to manage some of the assumptions they might make about my current role. I also acknowledged my female gender, which was the same as some participants and different from others. I reflected on the fact that all the participants would have different experiences of gender than mine. I also reflected on my previous experience as a support worker and considered how I might have responded to the questions and how my experiences were both similar and also different from those of the participants.

Commitment and rigour

Commitment to the research was demonstrated in both commitment to building a facilitative context for each participant interview, as outlined above in the development of relationships with each participant. It also required a commitment to the data and the analysis process, ensuring that each transcript was analysed in detail and according to the guidance set out in Smith et al. (2009). I also transcribed each interview, to establish and maintain closeness with the data. Sharing my analysis with my supervisors showed a commitment to an interpretation of the data that was not purely based on my own ideas but valued a diverse range of opinions and perspectives. I was aware of being a novice researcher, particularly new to IPA, so attempted to address this by reading about IPA, including examples of IPA research, attending and referring back to teaching at the university on qualitative methods and using supervision to access my supervisors’ knowledge and experience.

Rigour was demonstrated in the design of the study, considering carefully who suitable participants might be that would support the fulfilment of the research aims. The systematic conduct of the analysis that engaged with individual transcripts and made interpretations based on the meanings elicited from individual participants whilst also highlighting shared themes across the transcripts also demonstrated a commitment to rigour. It also felt important that quotes from multiple participants were available to support each theme and also that all participants were represented as equitably as possible throughout the analysis. Although this was attempted, it was also acknowledged that different participants had different amounts of experience and also varying levels of confidence in discussing underweight and engaging in the interview. This is discussed in the limitations section of the paper, alongside efforts that were made to support participants to feel comfortable within the interview, and suggestions of how this could be improved on in future. Credibility checks of the analysis were also conducted, in close contact with my supervisors throughout the analysis process to support the
checking and re-checking of themes. The analysis was also shared with a colleague with experience of qualitative research who was helpful in questioning each theme and its evidence base within the transcripts.

**Transparency and coherence**

Care has been taken to describe the procedure of the study in as much detail as possible, including the recruitment of participants, the development of the interview schedule and the analysis process. Verbatim quotes have been used within the paper and excerpts from the analysis process are included in the appendices to support the transparency of this research.

The assumptions and theoretical foundations of IPA as an approach, as discussed by Smith et al. (2009), have been considered throughout the research process to support this research to fit with it coherently. For example, I considered my position as interpreter of the data and participants’ experiences and tried to ensure that I was acting from this position throughout the research process.

**Impact and importance**

The discussion outlines the potential impact and implications of this research for staff and service users of learning disabilities services as well as researchers in this area. The topic was selected as it was considered to be an important topic with implications for the health and wellbeing of service users that had not been explored or researched in this way previously. A range of people were consulted in the process of developing this project, drawing on relevant clinical and research experiences. It is hoped that this research may facilitate further research in this or related areas and that either way, readers from different backgrounds will find something interesting and relevant to take from this paper.

**References:**


Appendix N: Data analysis process description  
(based on Smith et al., 2009)

1) Reflections
Following each interview, a reflection was written on the experience of it, which I referred back to when I started the analysis. This reminded me of my initial reactions to each interview and brought my attention to it as I started to analyse each transcript. This awareness helped to ensure that I explored alternative perspectives to my own and reminded me to seek evidence for anything that appeared to fit with these experiences (rather than just accepting assumptions).

2) Familiarising with the data
Each interview recording was listened to whilst reading the corresponding transcripts. I noticed significant non-verbal components, such as significant pauses or laughter. I also noted any contradictions that were present within the interview. I made notes on the most powerful recollections of the interview experience and my most striking observations about the interview. Again, noting these responses down explicitly drew my attention to what my initial reactions to each interview had been so that I could be aware of how the codes and themes that resulted from the data fit with these, encouraging me to broaden my analysis beyond these experiences.

3) Exploratory comments
Initial notes were made in the right-hand column, mostly related to the semantic content and use of language within the interview. Three types of notes were made, according to the IPA analysis procedure described by Smith et al. (2009): descriptive, linguistic and conceptual comments.

4) Developing emergent themes
From the comments, initial ideas for emergent themes were noted in the left-hand column. The idea for this was to reduce the volume of detail whilst maintaining complexity by mapping connections and patterns between notes.

5) Identifying evidence for themes
Similar themes were clustered together into broader themes and themes were amended to reflect the interpreted meaning behind each. The transcript was reviewed to identify quotes that acted as evidence to support the themes. The transcript was also reviewed to identify whether any further themes could be drawn from it. A table was made for each participant, with the themes identified from their transcript and a key phrase identified as evidence to support each theme.

The above was done for each interview in turn, with awareness of the importance of allowing new themes to emerge.

6) Looking for patterns across interviews
The themes identified for each interview were reviewed and compared to themes identified from other interviews, in order to identify connections and patterns between themes from different interviews. Themes from interviews that appeared to be connected were placed next to each other and consideration was given to possible higher-order concepts that multiple related themes may represent. Themes that were not supported by sufficient evidence or were not relevant across multiple interviews were discarded.

7) Final selection of themes
The themes that came into the final analysis were determined iteratively, based on relevance to the research question, supporting evidence and a sense of meaning and importance by the participants. Supporting quotes were identified and the transcripts were returned to in order to identify the context of the quote and support the interpretation of the meaning given to it by the participant.

8) Selection and adaptation of quotes
Quotes were identified as suitable for inclusion in the paper according to relevance to the theme and a sense that they supported the understanding of the underlying meaning of the theme for participants. Quotes were adapted to support understanding within the paper through the addition of explanatory words in square brackets and the use of dotted lines to indicate anything that has been considered unimportant to the quote and therefore removed.
References

## Appendix O: Transcript examples with coding

Stages (see Appendix N for further information):

1) Reflections

2) Familiarising with the data

3) Exploratory comments
   Three types of notes were made: **descriptive**, **linguistic** and **conceptual** comments.

4) Developing emergent themes

5) Identifying evidence for themes

### Audit trail 1: Nick

<table>
<thead>
<tr>
<th>Step 4</th>
<th>Transcript</th>
<th>Step 3</th>
<th>Step 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>581</td>
<td>I: Yeah, OK. Um, so, what, what’s it like for you when you’re supporting someone who’s underweight?</td>
<td><strong>Don’t treat.</strong> <strong>Underweight is seen as less urgent.</strong></td>
<td></td>
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<tr>
<td></td>
<td>Underweight seen as less pressing.</td>
<td><strong>Definitely.</strong> <strong>In what way? How do they treat it? How do they respond?</strong></td>
<td><strong>Who are ‘people’? Services or staff?</strong></td>
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<tr>
<td></td>
<td>P1: Um, it’s tricky but people definitely don’t treat it as urgent.</td>
<td><strong>One. Staff talk about overweight problems a lot.</strong> <strong>Constant. This is bad. She needs to lose weight. She’s getting too overweight.”</strong> <strong>Blah blah blah blah blah. “We need to organise this, we need to organise that. We need to do this.”</strong></td>
<td><strong>Treat in what sense? Treating a medical condition?</strong></td>
</tr>
<tr>
<td>583</td>
<td>I: OK.</td>
<td></td>
<td></td>
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<tr>
<td>584</td>
<td>P1: So again, going back to my previous job.</td>
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<tr>
<td>585</td>
<td>I: Yep.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Overweight is prioritised. Overweight is discussed regularly. Overweight is addressed with plans.</td>
<td><strong>One. Staff talk about the need to lose weight and what to do.</strong></td>
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</tr>
<tr>
<td>586</td>
<td>P1: The one who was very overweight, it was constant. Every day, the staff were like “This is bad. She needs to lose weight. She’s getting too overweight.” Blah blah blah blah blah. “We need to organise this, we need to organise that. We need to do this.”</td>
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<td></td>
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<tr>
<td>587</td>
<td>I: Yeah.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Underweight seen as less serious.</td>
<td><strong>Obviously. Underweight is less considered. Dramatised. What does that mean?</strong></td>
<td></td>
</tr>
<tr>
<td>588</td>
<td>P1: Whereas the underweight one, obviously she was seeing the doctor for it, but it wasn’t really…it’s wasn’t dramatised as much.</td>
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<td></td>
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<tr>
<td>589</td>
<td>I: OK.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Underweight discussed more casually.</td>
<td><strong>Said need to put weight on.</strong> <strong>Even the workers.</strong></td>
<td><strong>Sense of participant being different from “normal” support workers.</strong></td>
</tr>
<tr>
<td>590</td>
<td>P1: It was like, “Oh yeah, she still needs to put weight on.” It wasn’t as, like, so I think people still think. I think even, like, the workers, even thought that, you know.</td>
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<tr>
<td>591</td>
<td>I: Yeah.</td>
<td></td>
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<tr>
<td>592</td>
<td>P1: Obviously they knew she was too underweight. Awareness of too underweight. Obviously they knew.</td>
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<tr>
<td>593</td>
<td>I: Yeah</td>
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<td></td>
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<tr>
<td>594</td>
<td>P1: But they were, like, “Oh, underweight’s not as bad as being overweight”. Staff consider underweight less problematic. Not as bad. Tone? Did they say this? If not, how did it come across? Where did participant stand on this compared to “them”? In what way is underweight not as bad?</td>
<td></td>
<td></td>
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<tr>
<td>595</td>
<td>I: OK.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>596</td>
<td>P1: So the overweight ones are, like, “Critical danger.” Associate overweight with danger. Critical danger.</td>
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<td></td>
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<tr>
<td>597</td>
<td>I: Yeah, yeah.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>598</td>
<td>P1: “We have to do something before they’re dead.” But the underweight ones, it was, like, “Oh yeah, they, they’re, they just have to put a bit of weight on.” Like. Before they're lang. Less urgent for underweight. Just have to… What is behind this less urgency about underweight? Before they’re dead - very dramatic language.</td>
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<tr>
<td>599</td>
<td>I: OK. So it seems, to be, like you said, it, kind of, less dramatised.</td>
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<td></td>
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<tr>
<td>600</td>
<td>P1: Mmm.</td>
<td></td>
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<tr>
<td>601</td>
<td>I: There seems to be less drama around.</td>
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<tr>
<td>602</td>
<td>P1: Yeah, it wasn’t, like, obviously, it wasn’t. They didn’t brush off as normal, but it wasn’t seen as bad as being overweight. Obviously. Normal. Underweight isn’t brushed off. Underweight seen as less bad than overweight. Normal in what sense? How did they show they weren’t brushing it off? What did this look like?</td>
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</tbody>
</table>

**Stage 5:**

**16) Underweight is not prioritised by staff.**

*Underweight is seen as less problematic than overweight*

582 - It’s tricky but people definitely don’t treat it as urgent.

588-590 - Whereas the underweight one, obviously she was seeing the doctor for it, but it wasn’t really, it’s wasn’t dramatised as much. It was like, “Oh yeah, she still needs to put weight on.” It wasn’t as, like, so I think people still think. I think even, like, the workers.

594-598 - But they were, like, “Oh, underweight’s not as bad as being overweight”. So the overweight ones are, like, “Critical danger.” “We have to do something before they’re dead.” But the underweight ones, it was, like, “Oh yeah, they, they’re, they just have to put a bit of weight on.”

602 - They didn’t brush off as normal, but it wasn’t seen as bad as being overweight.
## Audit trail 2: Charlie transcript extract

<table>
<thead>
<tr>
<th>Step 4</th>
<th>Transcript</th>
<th>Step 3</th>
<th>Step 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>575</td>
<td>I: That’s great. Um, and what’s it like for you? Kind of, how, how do you find it supporting people who are underweight?</td>
<td>Difficult to support underweight person with learning disabilities. Challenging – contrast with confident tone – sounded easier earlier.</td>
<td>Does this contradict with just saying that aspects of it can be straightforward?</td>
</tr>
<tr>
<td>576</td>
<td>P2: Um, it’s challenging.</td>
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<td></td>
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<tr>
<td>577</td>
<td>I: Mmm</td>
<td>Judgements from others about care provided. Obviously. Managing judgements is most challenging thing?</td>
<td>Aware of judgements.</td>
</tr>
<tr>
<td>578</td>
<td>Judgements from others about underweight.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>579</td>
<td>I: Mmm hmm.</td>
<td>Judgements around care provided. Sore subject. Difficult topic to talk about. Why? What are the consequences of judgements?</td>
<td></td>
</tr>
<tr>
<td>580</td>
<td>P2: Or, you know, “You’re not doing your job right” or things like that. And it, it’s quite, quite a sore subject, like.</td>
<td>Parents find it difficult if child is underweight. Presumably, it wouldn’t be said this casually?</td>
<td>Judgements from parents.</td>
</tr>
<tr>
<td>581</td>
<td>I: Mmm hmm.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>582</td>
<td>P2: Especially if you tell a parent “Oh, your son’s underweight”.</td>
<td>Parents may think service not looking after properly. Confident in care providing but worried about others’ judgements.</td>
<td></td>
</tr>
<tr>
<td>583</td>
<td>I: Mmm.</td>
<td></td>
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<tr>
<td>584</td>
<td>P2: You know, they might think that we’re not feeding them properly when actually, you know you are.</td>
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<td></td>
</tr>
<tr>
<td>585</td>
<td>I: Yeah, yeah.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>586</td>
<td>P2: Um.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>587</td>
<td>I: So it can be quite a difficult conversation to have with parents.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>588</td>
<td>Hard to talk about underweight. P2: It can be quite difficult, yeah.</td>
<td>Hard to talk to parents about underweight. Quite difficult.</td>
<td>Quite difficult – what does this mean?</td>
</tr>
<tr>
<td>589</td>
<td>I: Yeah.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>590</td>
<td>Hard to monitor and support underweight. P2: Um, I do think it’s quite challenging working with it and, you know, making sure that “Oh, that resident’s underweight. OK, let’s make sure they get a lot of food.”</td>
<td>Difficult to work with underweight. Keeping track of underweight and food intake is hard.</td>
<td>Managing individual needs.</td>
</tr>
</tbody>
</table>
Staff encourage more food for underweight. Lots to keep on top of.

591 I: Mmm.

592 P2: And, you know, make sure they’re not doing as much exercise. So they’re not going to the gym for a couple of weeks.

Staff monitor exercise and try to reduce for underweight.

593 I: Mmm.

594 P2: You know, that kind of thing. Um, but yeah, it’s quite challenging.

Difficult to support underweight. Quite challenging. Don’t want to sound incompetent like can’t manage – again, afraid of judgement from me?

Stage 5:
7) Concern about being judged by others
Concern that they will be judged for poor care and neglect if a resident is underweight.
578, 580, 582, 584 - It is challenging because obviously you don’t want people to look at them and think “Oh, they’re, you’re not feeding them properly.” Or, you know, “You’re not doing your job right” or things like that. And it, it’s quite, quite a sore subject, like. Especially if you tell a parent “Oh, your son’s underweight.” You know, they might think that we’re not feeding them properly when actually, you know you are.

11) Staff monitoring and intervening in diet and activity
Can be challenging to keep track of everything
590, 592, 594 - I do think it’s quite challenging working with it and, you know, making sure that “Oh, that resident’s underweight. OK, let’s make sure they get a lot of food.” And, you know, make sure they’re not doing as much exercise. So they’re not going to the gym for a couple of weeks. You know, that kind of thing. Um, but yeah, it’s quite challenging.
Appendix P: Initial themes for each participant

Participant 1 (Nick):
Underweight caused by eating habits
2) Underweight caused by an inflexible eating routine
3) Sensory factors can restrict food intake
6) People with learning disabilities are less likely to eat foods they don’t like the taste of
18) Underweight caused by malnourishment from eating unhealthily

No single cause of underweight
5) Underweight caused by multiple factors
22) Uncertain what causes underweight
1) Being very active can cause underweight
15) Physical causes of underweight

Differences in eating of underweight residents compared to non-underweight residents
7) Food is prioritised less by underweight residents compared to other residents
8) Underweight residents have less of an appetite
9) Underweight residents not wanting to eat much

Trying to change eating habits of underweight residents
4) Importance of working together to change eating routines
14) Staff have to prompt and encourage underweight residents to eat more healthily

Challenges of supporting residents who are underweight
10) Staff can’t force people to eat healthily or to eat more if they are underweight
11) Residents not understanding the health consequences of underweight
21) Challenges of monitoring weight

Different attitudes of weight and body image of residents compared to adults without learning disabilities
12) Residents who are underweight are not influenced by media portrayals of weight
19) Adults with learning disabilities have a different attitude to body image

Environmental influences on underweight
13) Societal messages about being thin
17) Upbringing around weight is important and stays with residents

Staff attitude to residents’ weight
16) Underweight is not prioritised by staff
20) Staff don’t discuss weight often

Participant 2 (Charlie)
Residents lack understanding about underweight
4) Not understanding the relationship between weight and health
5) Interventions to address underweight in light of lack of understanding

Reasons for residents not eating
1) Underweight due to strict routines and rigidity
3) Underweight due to sensory difficulties around food
8) Not eating as a communication (of something physical?). 
9) Not eating as a choice 
10) Not eating because they don’t like the food being offered

Monitoring and responding by staff
2) Supporting underweight can require a change in routine
11) Staff monitoring and intervening in diet and activity
Can be challenging to keep track of everything
12) Weight monitoring
Procedures around weighing to ensure it happens and is responded to
13) Underweight is a physical health issue

Staff understand underweight as having a physical cause and respond accordingly

Other – external influences?
6) Residents not paying attention to media portrayals of weight
7) Staff are concerned about being judged by others

Participant 3 (Alex)
Causes of underweight
1) Underweight due to emotional factors
2) Individuals struggling to increase their weight
4) Environmental factors affecting eating
5) Underweight residents making themselves sick
11) Underweight can have physical causes

Supporting underweight
3) Interventions to support eating
6) It can be challenging for staff to support people who are underweight
12) Diet changes can be difficult for residents
13) Working together to support people who are underweight

Residents have a different understanding of weight than people without learning disabilities
7) Residents not understanding weight loss and not trying to lose weight intentionally
10) People with learning disabilities have a different understanding of the media and weight.

Indirect consequences of underweight
8) Underweight can cause anger for residents
9) Underweight can have an impact on activity

Participant 4 (Sam):
1) Lack of experience of underweight in residents.

7) Different reasons why residents aren’t eating
3) Underweight can be linked to depression.
6) Adults with learning disabilities can be underweight because they are neglected by staff.
9) Physical health difficulties could cause underweight

2) Underweight has an impact on how people are.

4) Managing underweight by supporting a sufficient and balanced diet.

Challenges of supporting underweight residents
5) Challenging if residents decline to eat
8) People with learning disabilities don’t understand how to address underweight

Participant 5 (Chris)
1) Using own experience that eating more helps to support residents who are underweight.
2) Managing underweight through feeding residents more.

7) Lots of different causes of underweight
3) Factors associated with underweight
5) Increased activity can cause underweight
6) Not eating to get attention

Staff monitoring weight on behalf of residents
4) People with learning disabilities don’t realise they are underweight
8) Staff respond to underweight by weighing these residents more regularly.
Participant 6 (Ashley)
Causes of underweight
1) Physical/genetic causes of underweight.
9) Underweight can be linked to distress or feeling upset about something.
12) Underweight residents can decline to eat
13) People with learning disabilities are more likely to have fluctuating weight
14) Particular rules or preferences can lead to underweight

Consequences of underweight
2) Mental health/emotional consequences of underweight.
3) Being underweight can lead to behaviour changes

Staff investigating weight
4) Monitoring weight is important
5) Investigating underweight is important.
6) People with learning disabilities can’t tell you why they are underweight

Joined-up response to underweight
7) Working with health professionals around underweight is important
8) Following plans to address underweight is important.
17) Supporting residents who feel anxious is important

Different understanding/perception of underweight by residents
10) Residents can have different perceptions or understandings of underweight at different times.
11) Residents may not understand why you are encouraging them to eat

Individualised support around weight
15) Knowing the residents is important for supporting them to have a healthy weight
16) Supporting underweight residents in a way that works for them is important

Participant 7 (Jo):
Identifying eating and weight changes
1) Regular weight monitoring
2) Monitoring eating
3) Highlighting and investigating weight loss

11) Different ways to support underweight
4) Following plans to address underweight
12) Responding to not eating
14) Supporting underweight residents to eat more
15) Adults with learning disabilities not understanding consequences of underweight

10) There are lots of different causes of underweight
5) Underweight because of a routine of not eating enough.
6) Routine changes could cause anxiety that could lead to weight loss
7) Anxiety can contribute to underweight
8) Physical causes of underweight.
9) Underweight as a consequence of being unable to communicate something

13) Staff members can’t force residents to eat

Participant 8 (Lou)
Different perceptions of underweight compared to overweight
1) People (staff and the public generally) are less concerned about underweight than overweight
7) Different understanding of underweight compared to overweight.

Staff support of eating in underweight residents
2) The importance of supporting healthy eating for underweight residents
3) Encouraging underweight residents to eat more.
5) Using drinks for additional nutrition for underweight residents.
17) How staff support residents around food depends on their weight.
18) Staff treat underweight residents differently around food.
4) Staff can’t force people to eat more.

8) The importance of investigating underweight
6) Possible health consequences for underweight residents.

Causes of underweight
9) Emotional causes of underweight
10) Lack of concentration by residents means that eating is not prioritised
11) The way residents eat can cause underweight.

13) Staff are responsible for residents’ weight
12) Lack of perseverance by staff could cause underweight.

Monitoring weight
14) Challenges of monitoring weight accurately.
15) Importance of monitoring weight through weighing and other methods.

Differences in underweight in adults with learning disabilities compared to adults without learning disabilities
16) Residents don’t understand the problems associated with underweight.
19) Residents are not underweight because of wanting to look a certain way.

Participant 9 (Jay)
Monitoring of eating and weight
1) Weight monitoring is important.
3) Staff monitor eating to prevent underweight.
4) Staff do extra monitoring of eating if residents lose weight.

Staff responses to weight loss
2) Teamwork and communication around weight
5) Staff seek advice around medical causes of weight loss.

13) There are many reasons why someone with learning disabilities might be underweight
6) Restricted choices of food could have an impact on weight
7) Weight loss not always related to a change in eating
11) People with learning disabilities could be underweight due to lack of support/monitoring

Lack of concern/knowledge about underweight
8) Lack of concern about underweight in society generally
9) Lack of concern about weight loss by GP
10) Own lack of knowledge about health consequences of underweight compared to overweight.

12) Difference in understanding about underweight between people with learning disabilities and people without learning disabilities

Participant 10 (Frankie)
Causes of underweight
1) Medical reasons for underweight.
2) Emotional causes of underweight.
3) Residents choosing to diet.
8) Residents can be underweight whilst eating a good diet.

Staff support of eating for underweight residents
4) Staff can’t force someone who is underweight to eat.
5) Encouraging underweight residents to eat.
Noticing and following up on weight changes
6) Monitoring weight regularly
7) Responding to weight loss

Participant 11 (Ali)
3) Individual causes of underweight
   1) Emotional causes of underweight.
   2) Medical causes of underweight
   5) Poor eating can cause underweight

Noticing and responding to underweight
4) Identifying underweight is harder than overweight
6) Noticing underweight visually
7) Responding to underweight
Part Two – Literature Review

What do we know about underweight in adults with learning disabilities?
A review of the literature

Statement of journal choice:

The Journal of Intellectual and Developmental Disability has been identified as an appropriate peer-reviewed journal for publication of this review. It has been selected because it publishes literature reviews in the area of learning disabilities. Its international and multi-disciplinary audience is important as this review is likely to be relevant and of interest to a range of health and care professionals. The journal focusses on the situation and concerns of people with learning disabilities and underweight in adults with learning disabilities is therefore within its remit.

7984 words
Abstract

**Background:** Adults with learning disabilities experience health inequalities, including barriers in accessing appropriate support. Obesity and underweight are more prevalent in adults with learning disabilities than in the general population but there appears to be more emphasis clinically and in research on obesity than underweight, although both are linked to physical and mental health difficulties. This review aimed to investigate, synthesise and evaluate current research evidence on underweight in adults with learning disabilities to gain insight into areas that require further exploration, namely that there appeared to be little research on underweight in adults with learning disabilities compared to obesity.

**Method:** A series of searches using identified search terms across five databases yielded 21 papers that met the criteria and were appraised critically for quality.

**Results:** Findings showed that research was focussed on two key themes: prevalence of underweight and factors associated with underweight.

**Conclusion:** Underweight appeared to be more prevalent in adults with learning disabilities and was associated with a range of factors. Although methodological limitations and discrepancies in definitions and techniques made it difficult to make comparisons across the studies, this review has implications for those supporting adults with learning disabilities, in identifying groups that may be at higher risk of underweight. Further research is required into the prevalence and factors associated with underweight that may support better understanding and lead to the development of interventions. Exploring the perspectives of staff working with adults with learning disabilities could be valuable to understand current practice in this area.
Introduction

Health inequalities experienced by people with learning disabilities are well-evidenced. One aspect of inequality appears to be underweight. This review explores the prevalence of underweight and factors associated with it in adults with learning disabilities.

Health inequalities in adults with learning disabilities

The fact that people with learning disabilities die, on average, 15-20 years earlier than the general population\(^2\) (Learning Disabilities Mortality Review, 2017) is indicative of health inequality. Groups such as Mencap advocate for the rights of people with learning disabilities and present evidence of institutional discrimination that has led to poorer healthcare (Mencap, 2007) and higher unmet need (Michael, 2008). Mencap provided examples of people with learning disabilities who had experienced what Mencap understood as avoidable deaths caused by institutional discrimination. Although they acknowledged that it was not possible to know whether discrimination was conscious, they highlighted that unintentional discrimination is still unlawful (Disability Discrimination Act, 2005; Equality Act, 2010). People with learning disabilities may have difficulty accessing healthcare due to lack of reasonable adjustments and poor co-ordination of care (Heslop et al., 2013). Diagnostic overshadowing may lead clinicians to attribute symptoms to the learning disability rather than to physical or mental health conditions (Day and Jancar, 1994) and so not investigate them.

\(^2\) ‘General population’ is the term used most widely to describe adults without learning disabilities.
This vulnerability of adults with learning disabilities to poorer physical and mental health led to the introduction of annual health checks in 2008 as a reasonable adjustment to support access to healthcare (Department of Health [DoH], 2013). Although the take-up of annual health checks is increasing, only 55.1% of patients with learning disabilities received one in 2017/18 (NHS Digital, 2019), suggesting that further action is required to support equal access to healthcare.

**Weight in adults with learning disabilities**

Annual health checks include a weight check (NHS Choices, 2018) as weight is considered important and potentially problematic for adults with learning disabilities. 2-35% of adults with learning disabilities are obese and 5-43% are significantly underweight (Gravestock, 2000). This range of prevalence may relate to different definitions and methodologies between studies, which prevented Humphries, Traci and Seekins (2009) from doing a meta-analysis of weight research. They concluded that the distribution of body weight for adults with learning disabilities was outside the normal range and poor weight status at both extremes is concerning.

The Royal College of General Practitioners’ annual health check guidance (Hoghton, Lamb & Van Dam, 2017) includes overweight and obesity as the first part of the baseline physical examination, citing these as major health risk factors for people with learning disabilities. Hoghton et al. suggested reasons for overweight in adults with learning disabilities, including lack of knowledge, support or healthy role models, and described weight loss interventions. Much research has been conducted on overweight
in adults with learning disabilities, leading to reviews on prevalence (Rimmer & Yamaki, 2006) and interventions (Spanos, Melville & Hankey, 2013).

In contrast, the only mention of low weight in Hoghton et al.’s (2017) guidance is as a risk factor for low bone mineral density in people with cerebral palsy. There was no definition of underweight and no mention of associated health difficulties. The World Health Organisation ([WHO], 2019) define underweight as a BMI of 18.5 or under and describe health risks, including reduced immune system capacity, which can increase mortality from infectious diseases (WHO, 2002). Heslop et al.’s (2013) Confidential Inquiry into premature deaths of people with learning disabilities, (CIPOLD) found a lower median age at death for people who were underweight than any other weight category, suggesting that underweight is associated with poor health and mortality in adults with learning disabilities. However, as this was reported as an association, it is not possible to infer causation from these findings.

There is no corresponding section in Hoghton et al.’s (2017) guidance on assessing and managing underweight in this population, as there is for obesity. Heslop et al. (2013) related underweight to ‘inadequate knowledge about nutrition by care staff’ leading to ‘lack of awareness and recognition of malnutrition in some deaths’ (p.84). They described weighing as important in recognising malnutrition and reported barriers to weighing adults with learning disabilities, such as lack of appropriate scales.

The greater emphasis on overweight than underweight appears to extend beyond the annual health checks and into the research arena and it was not possible to find any reviews on underweight specifically in adults with learning disabilities similar to those on obesity.
Interestingly, a review that acknowledged the problematic higher prevalence of both overweight and underweight in adults with learning disabilities only mentioned interventions for obesity and stated that less is known about the risks for underweight (Humphries et al., 2009). Heslop et al. (2013) found that dependence on others for eating was a significant contributory factor for premature deaths in people with learning disabilities compared to the general population. They quoted the sister of someone with a learning disability who had died prematurely who suggested that her relative was not eating prior to their death and did not receive sufficient support. Difficulties around supporting feeding in people with learning disabilities could be an emotive topic and something on which further staff training is required.

Gravestock (2000) argued that previous reviews had not paid sufficient attention to the contribution of eating disorders to underweight and the biopsychosocial impact of these conditions in this population. His review included atypical eating disorders and reported that 3-42% of institutionalised adults with learning disabilities and 1-19% of adults with learning disabilities living in the community had diagnosable eating disorders. The range and uncertainty of these estimates points to diagnostic and methodological difficulties (Gravestock, 2000). Jones and Samuel’s (2010) review of eating disorders in adults with learning disabilities found a lack of consensus about understanding, assessment, diagnosis and treatment. Gravestock’s (2003) adapted classification system had aimed to overcome this. Allowing symptoms to be reported by others to compensate for difficulties eliciting these directly from adults with learning disabilities raises the question of how these eating disorders equate to those in the general population.
There is little research on eating disorders in adults with learning disabilities, suggesting that they may be considered less relevant, or are more difficult to diagnose and therefore not recognised. Cicmil and Eli (2014) reported six case studies of people with learning disabilities and anorexia nervosa, which includes underweight. Kachani and Cordás’ (2011) literature review of anorexia nervosa in adults with learning disabilities concluded that treatment had not been established but required specific team training. Unfortunately, only the abstract of Kachani and Cordás’ paper is available in English. Gravestock (2000) also recommended staff training around underweight and its physical, mental and psychosocial comorbidities (including eating disorders). The literature currently available on eating disorders in adults with learning disabilities consists mostly of case studies and reviews as little research has been conducted in this area.

Overall, it appears that although there may be a higher prevalence of underweight among adults with learning disabilities than in the general population, with potential health consequences, it is receiving less attention than overweight.

*Rationale*

Investigations by Mencap (2007) and CIPOLD (Heslop et al., 2013) highlight health inequalities experienced by adults with learning disabilities. Unhealthy weight at either extreme is concerning and appears to be more prevalent in adults with learning disabilities than the general population. Obesity in adults with learning disabilities has been well-researched and is included in annual health checks, however there appears to have been less attention to underweight. Underweight also has physical health
consequences and is associated with eating disorders such as anorexia nervosa that have physical, mental and psychosocial comorbidities. Adults with learning disabilities often rely on assistance from others to meet their health needs and lack of awareness among staff about malnutrition and eating disorders (both of which have been related to underweight) have been highlighted by Heslop et al. (2013) and Gravestock (2000) respectively. This suggests that adults with learning disabilities may not receive adequate support with underweight and its associated health risks. The apparently disparate level of interest in underweight compared to overweight in adults with learning disabilities suggests that it is worthy of further investigation.

**Aims**

The aim of this review was to investigate, synthesise and evaluate current research evidence on underweight in adults with learning disabilities, to provide insight into gaps in the current research literature that require further exploration.

**Method**

**Search methodology**

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) (Moher, Liberati, Tetzlaff & Altman, 2009) guidelines were followed to collect and report data for this review (Figure 1).

**Database search strategy**

A series of searches were conducted simultaneously across the following databases: PsychInfo, MedLine, Cinahl, PsychArticles, Psychology and Behavioural Sciences Collection, initially on 26th June 2018 and then on 21st March 2019, at which point one
article was added. Search terms were developed from examining phrases used in relevant articles that had already been identified and considering the variety of language used to describe related concepts. The searches were limited to articles published from 1998 onwards to acknowledge the significant changes in how health and wellbeing are considered in adults with learning disabilities. Valuing People (DoH, 2001) chartered a change in approach around the start of the 21st century, so it was considered most helpful to review more contemporary literature. It was also necessary for the searches to retrieve a manageable number of results. Table 1 sets out the criteria for each search. Although the term ‘learning disabilities’ has been used throughout this review as the most prevalent term within the UK, alternative terms were also used in searches to identify papers written in different countries or at different times.

Table 1: Search terms and results

<table>
<thead>
<tr>
<th>Search no</th>
<th>Search terms</th>
<th>Search results</th>
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<tbody>
<tr>
<td>1</td>
<td>(“learning disabilities” or “intellectual disabilities” or “mental retardation” or “learning difficulties” or “special needs” or “mental handicap”) AB Abstract AND (underweight or thin or thinness) AB Abstract</td>
<td>263</td>
</tr>
<tr>
<td>2</td>
<td>(“learning disabilities” or “intellectual disabilities” or “mental retardation” or “learning difficulties” or “special needs” or “mental handicap”) AB Abstract AND (malnutrition or undernutrition or undernourishment) AB Abstract</td>
<td>102</td>
</tr>
<tr>
<td>3</td>
<td>(“learning disabilities” or “intellectual disabilities” or “mental retardation” or “learning difficulties” or “special needs” or “mental handicap”) AB Abstract AND “weight loss” AB Abstract</td>
<td>89</td>
</tr>
<tr>
<td>4</td>
<td>(“learning disabilities” or “intellectual disabilities” or “mental retardation” or “learning difficulties” or “special needs” or “mental handicap”) AB Abstract AND “food refusal” AB Abstract</td>
<td>22</td>
</tr>
<tr>
<td>5</td>
<td>(“learning disabilities” or “intellectual disabilities” or “mental retardation” or “learning difficulties” or “special needs” or “mental handicap”) AB Abstract AND “low weight” AB Abstract</td>
<td>9</td>
</tr>
<tr>
<td>6</td>
<td>(“learning disability” or “intellectual disability” or “learning difficulty”) AB Abstract AND (underweight or thin or thinness) AB Abstract</td>
<td>126</td>
</tr>
</tbody>
</table>
These searches led to 1163 results, with an additional 11 papers sourced by hand-searching of reference lists, leading to a total of 1174 results prior to the removal of duplicates.

**Study Selection**

The PRISMA flowchart (Figure 1) illustrates the process of screening and assessing articles for eligibility. Following the exclusion of duplicate articles, titles and abstracts were screened for adherence to the inclusion and exclusion criteria (Table 2). Following this, articles were read and assessed again according to the inclusion and exclusion criteria.
Figure 1: PRISMA literature search diagram

Identification

Search terms identified and refined.
Records identified through database searching
n = 1163
Records after duplicates removed
n = 781
Duplicates excluded
n = 382
Records identified through hand searching of reference lists
n = 11

Screening

Records screened
n = 792
Records excluded (n = 683)
1) Article does not refer to learning disabilities (WHO definition) (n = 81).
2) Article refers solely to children or adolescents (under 18 years old) (n = 249).
3) Article does not discuss underweight (n = 217).
4) Case studies/vignettes of individuals (n = 32).
5) Article refers to one specific rare genetic or complex condition rather than learning disabilities more broadly (n = 49).
6) Article refers to learning disabilities and underweight but not together (n = 52).
7) Articles referencing concepts such as malnutrition/weight loss without mentioning underweight (n = 3).
8) Not a peer reviewed published article (n = 8).
9) Full article not available in English (n = 2).

Eligibility

Full text articles assessed for eligibility
n = 99
Full text articles excluded (n = 79)
1) Article refers solely to children or adolescents (under 18 years old) (n = 2).
2) Article does not discuss underweight (n = 35).
3) Case studies/vignettes of individuals (n = 16).
4) Article refers to one specific rare genetic or complex condition rather than learning disabilities more broadly (n = 4).
5) Article refers to learning disabilities and underweight but not together (n = 3).
6) Articles referencing concepts such as malnutrition/weight loss without mentioning underweight (n = 7).
7) Not reporting a piece of research (n = 5).
8) Not a peer reviewed published article (n = 2).
9) Published outside of search time period (1998-2018) (n = 3).
10) Full article not available in English (n = 2).

Included

Studies included in initial synthesis
n = 20

Studies included in final synthesis
n = 21

Articles found during second literature searches
(n = 1)
Table 2: Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Article reporting research about adults with learning disabilities (WHO definition).</td>
<td>Article does not refer to learning disabilities (WHO definition).</td>
</tr>
<tr>
<td>Analysis includes underweight in adults with learning disabilities.</td>
<td>Article refers solely to children or adolescents (under 18 years old).</td>
</tr>
<tr>
<td>Article reporting research investigating factors associated with underweight in adults with learning disabilities.</td>
<td>Case studies/vignettes.</td>
</tr>
<tr>
<td>Published in English in a peer-reviewed journal between 1998-2019.</td>
<td>Article refers to one specific rare genetic or complex condition rather than learning disabilities more broadly.</td>
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<tr>
<td></td>
<td>Article refers to learning disabilities and underweight but not together.</td>
</tr>
<tr>
<td></td>
<td>Articles referencing concepts such as malnutrition/weight loss without mentioning underweight.</td>
</tr>
<tr>
<td></td>
<td>Not reporting a piece of research.</td>
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<tr>
<td></td>
<td>Not a peer reviewed published article.</td>
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<tr>
<td></td>
<td>Full article not available in English.</td>
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<tr>
<td></td>
<td>Article does not include underweight in the analysis.</td>
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</table>

Case studies were excluded due to describing individuals rather than a larger sample of the population. Similarly, papers only referring to specific and rare genetic conditions were excluded as their findings were likely to be less generalisable. Papers including only children and adolescent participants were excluded to yield a more focussed body of evidence. Restricting the search to peer-reviewed published articles aimed to increase the quality of research included. Although publication bias may have affected which articles were published, including articles with different methods and populations attempted to mitigate this. Many of the articles employed cross-sectional designs. Whilst it is acknowledged that the inclusion of non-experimental research in literature reviews has been questioned (Shrier et al., 2007), the early and exploratory stage of research in this area meant that this review explored what the research reports currently about underweight in adults with learning disabilities. Many of these studies investigated factors associated with underweight (rather than interventions to address
it), for which it would be difficult practically and ethically to conduct an experimental study. These studies were therefore included. Whilst relevant studies would have been included of either quantitative or qualitative design, all the studies used quantitative methodology and one included qualitative elements as part of a mixed design.

Data extraction, evaluation and synthesis

The process above yielded 21 articles suitable for inclusion in the review. As there is no consensus about the best quality assessment tool for studies with ex post facto designs (Jarde, Losilla & Vives, 2012), it was decided to use the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet, Lee & Cook, 2004) to appraise critically and assess the quality of each article. This tool was chosen because it allows quality appraisal across a variety of designs and methods and allows the exclusion of some non-applicable criteria.

A narrative data synthesis approach was used. Each eligible article was read in full before the relevant data was extracted. Table 3 shows the focus, participants, sample characteristics, design and analysis, sampling and relevant data collection, key relevant findings and quality rating based on Kmet et al. (2004). Magnitudes of association in the form of odds ratios were extracted from each paper or calculated by hand where possible. This was considered more helpful than magnitudes of effect as most of the papers were investigating factors associated with underweight rather than experimental data or interventions. As the information required for this calculation was often not reported within the paper, the authors were contacted to request this data (Appendix B). Significant factors for which odds ratios were available are presented in Table 4. Additional information about each study can be found in Appendix C.
Table 3: Characteristics and findings of studies included in the review

<table>
<thead>
<tr>
<th>Paper, location and quality rating</th>
<th>Focus</th>
<th>Participants</th>
<th>Sample Characteristics</th>
<th>Design and Analysis</th>
<th>Sampling and relevant data collection</th>
<th>Key relevant findings</th>
</tr>
</thead>
</table>
| **Batista et al. (2009)** Brazil. 75% | Oral health and nutritional status. | ‘Semi-institutionalised’ people with learning disabilities. | N = 200
Response rate: 68%.
Gender: 91 (45.5%) female, 109 (54.5%) male.
Age: range = 5-53 (mean/s.d. not stated).
Ethnicity: Not stated. | Quantitative - Cross-sectional.
Chi-square test. | Convenience sampling.
- Medical examination (oral health status).
- BMI measurement. | - 7% of participants were underweight.
- Oral health status did not relate to underweight. |
Response rate: 100% (included everyone on register).
Gender: 458 (41%) female, 661 (59%) male.
Age: 20 and over (range/mean/s.d. not stated).
Ethnicity: 88.4% white, 9.2% South Asian, 2.4% other. | Quantitative - Cross-sectional.
Univariate analysis. Logistic regression. | Convenience sampling.
- Health check (BMI, physical and mental health co-morbidities).
- Interview (health and activity variables). | - 18.6% of participants were underweight.
- Women with learning disabilities were 2.35 more likely to be underweight than women without learning disabilities.
- Men with learning disabilities were 8.44 more likely to be underweight than men without learning disabilities.
- Underweight was more prevalent in male participants (21%) than in female participants (16%) (p = .03).
- Underweight was associated with younger age (p = .004), absence of Down syndrome (p = .006) and not taking medication (p = .008). |
<table>
<thead>
<tr>
<th>Study</th>
<th>Countries</th>
<th>Nutritional consequences of resettlement from a large learning disabilities hospital into small community homes.</th>
<th>Adults with learning disabilities resettled from a long-stay hospital.</th>
<th>N = 121. Response rate: Gender: 44 (36%) female, 77 (64%) male. Age: mean, range and s.d. not stated. Ethnicity: not stated.</th>
<th>Quantitative - Longitudinal cohort study. McNemar’s test.</th>
<th>Convenience sampling. - Questionnaire (weight, nutritional adequacy and nutrition-related problems).</th>
<th>- More female participants were underweight than male participants. - Participants were more likely to be underweight after moving to small community homes from a large learning disabilities hospital (16% compared to 14%). - There was a significant shift to unintentional weight loss after the move (p = .001). For women, p = .041. For men, p = .015.</th>
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<tr>
<td>Bryan et al. (2000) UK 64%</td>
<td>Nutritional consequences of resettlement from a large learning disabilities hospital into small community homes.</td>
<td>Adults with learning disabilities resettled from a long-stay hospital.</td>
<td>N = 121. Response rate: Gender: 44 (36%) female, 77 (64%) male. Age: mean, range and s.d. not stated. Ethnicity: not stated.</td>
<td>Quantitative - Longitudinal cohort study. McNemar’s test.</td>
<td>Convenience sampling. - Questionnaire (weight, nutritional adequacy and nutrition-related problems).</td>
<td>- More female participants were underweight than male participants. - Participants were more likely to be underweight after moving to small community homes from a large learning disabilities hospital (16% compared to 14%). - There was a significant shift to unintentional weight loss after the move (p = .001). For women, p = .041. For men, p = .015.</td>
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<td>Eden &amp; Randle-Phillips (2017) UK 73%</td>
<td>i) Concepts for underweight, overweight and healthy weight among adults with learning disabilities, and ability to apply these to themselves. ii) Body perception bias and body dissatisfaction of young adults with learning disabilities compared to young adults without learning disabilities.</td>
<td>Young adults with and without learning disabilities attending educational courses.</td>
<td>N = 88. Response rate: 18% of colleges agreed to participate. Age: 16-25. 40 (45%) adults with learning disabilities. Gender: 20 (50%) female, 20 (50%) male. Age: mean = 20.3, s.d. = 2.4. Ethnicity: White British = 82.5%, Indian = 5.0%, Black = 12.5%. 48 (55%) adults without learning disabilities. Gender: 20 (42.5%) female, 28 (57.5%) male. Age: mean = 17.8, s.d. = 1.5. Ethnicity: White British = 52.1%</td>
<td>Mixed: Quantitative – Correlational and ex post facto. Qualitative – Interview. Fisher’s exact tests. Wilcoxon signed ranks tests. Spearman’s correlation coefficient. Content analysis.</td>
<td>Convenience sampling. - BMI measurement. - Questionnaire. - Body perception rating scale. - Interview (weight and body satisfaction).</td>
<td>- Participants with learning disabilities were more likely to be underweight than participants without learning disabilities (15.4% compared to 10.4%) (p &lt; .001). - Participants with learning disabilities could not distinguish between healthy weight and underweight, however appeared to conceptualise underweight correctly as smaller than healthy weight. - Participants with learning disabilities did not apply generalised rules for body size to themselves. - Participants with learning disabilities demonstrated a marginal body perception bias (p = .046). - Female participants with learning disabilities were likely to underestimate their body size</td>
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<td>Quality of support (shown by different health outcomes including weight) of adults with learning disabilities living in cluster housing compared to those living in dispersed housing.</td>
<td>Adults with learning disabilities in supported accommodation.</td>
<td>N = 910. Response rate: not stated. 169 (18.5%) adults living in cluster housing Gender: 69 (41%) female, 100 (59%) male. Age: mean = 46.4. Age range and s.d. not stated. Ethnicity: White = 97%. Other = 3%. 741 (81.5%) adults living in dispersed housing Gender: 348 (47%) female, 393 (53%) male. Age: mean = 50.4. Age range and s.d. not stated. Ethnicity: White = 99%. Other = 1%.</td>
<td>Mixed – convenience and random/non-random sampling. Quantitative - Cross-sectional. Logistic regression analyses and PLUM ordinal regression analyses.</td>
<td>Participants in cluster housing were more likely to be underweight (% not reported) (p &lt; .05) than participants in dispersed housing.</td>
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<td>Emerson (2004)</td>
<td>UK</td>
<td>73%</td>
<td>White other = 6.3%, Mixed Ethnicity = 14.6%, Indian = 4.2%, Black = 18.8%, Arab = 4.2%.</td>
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<td>Ireland</td>
<td>N = 131. Response rate: 6.9%. Gender: 54 (41%) female, 77 (59%) male. Age: Range = 16-64. Age mean/s.d. not stated. Ethnicity not stated.</td>
<td>N = 131. Response rate: 6.9%. Gender: 54 (41%) female, 77 (59%) male. Age: Range = 16-64. Age mean/s.d. not stated. Ethnicity not stated.</td>
<td>- 2.4% of participants were underweight, compared to 2% in the general population. - When asked about their weight, 8.4% of participants said they were ‘too light’. - No participants reported that they had been advised by a health professional to gain weight. - The mean reported energy intake was 1890 kcal/day. - More male participants were underweight than female.</td>
<td>- Female participants were more likely to be underweight than women who did not have learning disabilities at all ages above 35. - More male participants were underweight than female participants. - Underweight was associated with younger age and severity of learning disabilities.</td>
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<td>Hove (2004a)</td>
<td>Prevalence of eating disorders in adults with learning disabilities and comparison with the general population.</td>
<td>N = 304. Response rate: 75%. Gender: Incorrectly stated (% do not add to 100). Age: range = 17-85, mean = 39. Age s.d. not stated. Ethnicity not stated.</td>
<td>Quantitative - Cross-sectional. Chi-square tests.</td>
<td>Convenience sampling. - Questionnaire (clinical, demographic and eating information). - BMI measurement (or taken from records).</td>
<td>Incidence of anorexia nervosa (1.6%) was higher than the general population (% not reported). Participants with severe learning disabilities were more likely to have anorexia nervosa (p &lt; .001). Participants aged 18 to 39 were more likely to have anorexia nervosa than older participants (p = .042). Cerebral palsy was related to indices of anorexia nervosa (p &lt; .0001). Epilepsy was related to indices of anorexia nervosa (p = .043). There was a higher prevalence of anorexia nervosa in male participants.</td>
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<tr>
<td>Hove (2004b)</td>
<td>Prevalence of underweight and obesity among adults with learning disabilities and comparison with the general population.</td>
<td>N = 282. Response rate: 75%. Gender: 139 (49%) female, 143 (51%) male. Age: range, mean and s.d. not stated. Ethnicity: not stated.</td>
<td>Quantitative - Cross-sectional. Chi-square tests. One-way ANOVA.</td>
<td>Convenience sampling. - Questionnaires (BMI and health and support information).</td>
<td>7.8% participants were underweight. Male participants were more likely to be underweight compared to the general population (9.1% compared to 3%). Participants with severe learning disabilities were more likely to be underweight (p &lt; .01). Food refusal (p &lt; .05) and self-induced vomiting (p &lt; .01) was more present among underweight participants. Dependence was more present in underweight participants (p &lt; .001).</td>
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<tr>
<td>Study</td>
<td>Location</td>
<td>Study aim</td>
<td>Study design</td>
<td>Sample size</td>
<td>Response rate</td>
<td>Gender</td>
<td>Age</td>
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</table>
| Jolly & Jamieson (1999) | UK | 50% | i) Nutritional problems affecting adults with severe learning disabilities living in the community.  
ii) Effectiveness of intervention by a dietitian. | Adults with severe learning disabilities referred to a dietitian. | N = 45. Response rate: 100% (included everyone referred). Gender: 26 (58%) female, 19 (42%) male. Age: range = 22–73, mean = 37. Age s.d. not stated. Ethnicity: not stated. | Quantitative - Longitudinal pre-test/post-test. Description and comparison – no statistical analysis. | Convenience sampling. - BMI measurement. | - The most predictive independence variable for underweight was assisted feeding (p < .0001).  
- 33% of participants were underweight.  
- More male participants were underweight than female (37% compared to 31%).  
- Dietetic intervention was associated with improved BMI. |
i) Weight and intervention for adults with learning disabilities.  
ii) Impact of health promotion classes on weight. | Young people and adults with learning disabilities attending special services.  
- Questionnaire (health history, diet, exercise).  
- Clinic check (physical health check).  
- Questionnaire (outcome of referrals/recommendations).  
Study 2) Purposive/Voluntary sampling. | - 16.7% of participants were underweight.  
- Significantly more younger participants were classed as ‘underweight’ compared to older participants (no significance provided).  
- No differences in BMI banding by gender (p = .538), accommodation setting (p = .429) or mobility (p = .232) were identified. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Sample Description</th>
<th>Sample Size</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Study Design</th>
<th>Data Collection</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>McGuire et al. (2007) Ireland</td>
<td>64%</td>
<td>Survey of health behaviours (including weight) of adults with learning disabilities.</td>
<td>N = 157.</td>
<td>Gender: 73 (46.5%) female, 84 (53.5%) male. Age: range = 16-65, mean = 37, s.d. = 11.73. Ethnicity: not stated.</td>
<td>Quantitative – Cross-sectional. Descriptive statistics (mean and s.d.). Independent t-tests for gender differences.</td>
<td>Random sample selected from convenience sample.</td>
<td>BMI measurement.</td>
<td>- One person (2%) who was underweight had raised blood pressure.</td>
<td></td>
</tr>
<tr>
<td>Molteno et al. (2000) South Africa</td>
<td>65%</td>
<td>Nutritional status and weight of adults with learning disabilities.</td>
<td>N = 615.</td>
<td>Gender: 302 (49%) female, 313 (51%) male. Age: range, mean and s.d. not stated. Ethnicity: not stated.</td>
<td>Quantitative – Cross-sectional. Chi-square.</td>
<td>Convenience sampling.</td>
<td>BMI measurement.</td>
<td>2.3% of participants were underweight.</td>
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</tr>
<tr>
<td>Moore et al. (2004) Australia</td>
<td>73%</td>
<td>Weight distribution of adults with learning disabilities.</td>
<td>N = 93</td>
<td>Gender: 41 (44%) females, 52 (56%) males. Age: Females: range = 19-58, mean = 33.57, s.d. = 9.26. Males: range 18-63, mean = 31.46, s.d. = 9.62. Ethnicity: not stated.</td>
<td>Quantitative – Cross-sectional. Independent t-test. Correlation. Chi-square analysis.</td>
<td>Convenience sampling.</td>
<td>BMI, waist:hip ratio and percentage body fat measurements.</td>
<td>- 6% of participants were underweight, compared to 6.5% in the general population. - There were more underweight male participants (7.6%) than female participants (4.9%). - There was no relationship between living environment and BMI classification.</td>
<td></td>
</tr>
<tr>
<td>Country/City</td>
<td>Study Title (Year)</td>
<td>Details</td>
<td>Prevalence</td>
<td>Study Design</td>
<td>Ethnity</td>
<td>BMI Status</td>
<td>Sample Size</td>
<td>Response Rate</td>
<td>Gender</td>
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<tr>
<td>Australia</td>
<td>64%</td>
<td>Caries and BMI in Special Olympics athletes.</td>
<td>64%</td>
<td>Descriptive statistics and chi-square.</td>
<td></td>
<td>- Dental status assessed by volunteer dentists.</td>
<td></td>
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</tr>
<tr>
<td>UK</td>
<td>65%</td>
<td>Robertson et al. (2000) Prevalence of risk factors for poor health (including weight) among people with learning disabilities.</td>
<td>65%</td>
<td>Quantitative – cross-sectional. Logistic regression, ANOVA and chi-square.</td>
<td></td>
<td>- 22.7% of participants were underweight.</td>
<td>N = 500</td>
<td>Response rate: 93%. Gender: 200 (40%) females, 300 (60%) males. Age: mean = 45.1, range/s.d. not stated. Ethnicity: 97% white, 3% other.</td>
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<tr>
<td>International</td>
<td>90%</td>
<td>Temple et al. (2014) i) BMI status by world region and gender for Special Olympics athletes. ii) Factors associated with BMI.</td>
<td>90%</td>
<td>Convenience and random sampling. - Questionnaires (about service and participants - weight, physical and mental health information).</td>
<td></td>
<td>- 5.5% of participants were underweight.</td>
<td>N = 11 643</td>
<td>Response rate: 100% (included everyone’s records). Gender: 4493 (39%) female, 7150 (61%) male. Age: Females: mean = 30.4, s.d. = 10.2. Age range not stated. Males: mean = 29.6, s.d. = 9.9. Age range not stated. Ethnicity: not stated.</td>
<td></td>
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<tr>
<td>China</td>
<td>65%</td>
<td>Tsai et al. (2011) Screening for risk of under- and over-nutrition (including weight) in adults with learning disabilities.</td>
<td>65%</td>
<td>Quantitative - Cross-sectional. Binary logistic regression.</td>
<td></td>
<td>- 12.5% of participants were underweight.</td>
<td>N = 104</td>
<td>Response rate: 43%. Gender: 45 (43%) female, 59 (57%) male. Age: range = 19-72.</td>
<td></td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Percent</td>
<td>Study Objective</td>
<td>Sample Characteristics</td>
<td>Methodological Details</td>
<td></td>
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<tr>
<td>Wong (2011)</td>
<td>Hong Kong</td>
<td>71%</td>
<td>Health status profile (including weight) and healthcare needs of adults with learning disabilities.</td>
<td>N = 811 Gender: 379 (46.7%) females, 432 (53.3%) males. Age: range = 18-79, mean = 44. Age s.d. not stated.</td>
<td>Quantitative - Cross-sectional. Description and comparison – no statistical analysis. Convenience sampling (incorrectly reported as purposive sampling). - Survey questionnaire (health, BMI). - 25.4% of participants were underweight (over twice as prevalent as in the general population). - Underweight was associated with younger age. - More male participants were underweight than female.</td>
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</table>
Results

Overview of studies included

Table 3 summarises the important characteristics of each paper included in this review. 20 studies used quantitative methodology with one using mixed methodology, incorporating qualitative and quantitative analysis. 17 of the 21 studies used non-experimental cross-sectional designs. The remaining studies used longitudinal pre-test/post-test, longitudinal cohort, cross-sectional and longitudinal designs. The sample sizes varied from 45 to 11,643 participants and the total number of participants across the studies was 19,389. One study (Hove, 2004a) appeared to have made an error in their reporting of gender but of the rest, 40.9% (7807) of participants were female. 15 studies used convenience sampling strategies, with five studies using mixed sampling methods and one (Verstraelen, Maaskant, van Knijff-Raeven, Curfs & de Valk, 2009) using stratified random sampling. Sixteen of the studies were conducted in Western countries, with eight in the UK, three in Australia, two in Ireland, two in Norway and one in the Netherlands. One study was conducted in each of Brazil, South Africa, Taiwan and Hong Kong and one study was conducted in Canada but included participants from all over the world. Participants were all adults with learning disabilities, other than in one study (Eden & Randle-Philips, 2017), which compared half of their sample with learning disabilities with the other half without learning disabilities. Participants were recruited from a variety of settings, including community teams (n = 4), residential services (n = 7), hospital/institutions (n = 4), the Special Olympics (n = 2), day centres (n = 1) and specialist colleges (n = 1). Two studies appeared to recruit participants from a variety of settings.
Quality appraisal

The quality ratings using Kmet et al.’s (2004) approach are listed in the first column of Table 3 (see Appendix D for full quality assessment) and ranged between 50% and 91%, suggesting that the quality varied widely. It must be acknowledged that one paper (Jolly & Jamieson, 1999) fell below 55%, which Kmet et al. (2004) considered a liberal threshold for inclusion in reviews. However, due to the small number of papers focussing in detail on this area of research, it was decided to include it, although the lower quality of the paper was noted throughout the analysis and the results were treated more cautiously than those of papers with higher quality ratings. Common limitations of the papers were not providing estimates of variance such as confidence intervals, and not controlling for potentially confounding variables when comparing underweight in adults with learning disabilities to the general population. The studies also varied in quality in terms of the selection and description of participants. These limitations will be explored further in the Discussion.

Synthesis of main findings

The aim of this review was to explore this area of literature to develop an overview of the current knowledge base. The findings from each study were extracted and organised into themes based on similarity of content. This synthesis led to two main themes, which were prevalence of underweight in adults with learning disabilities and factors associated with underweight in adults with learning disabilities. An additional finding of problems associated with underweight was also identified. These themes are described further below.
Prevalence of underweight in adults with learning disabilities

The prevalence of underweight in these studies varied from 0% (Koritsas & Iacono, 2016) to 29% (Molteno, Smit, Mills & Huskisson, 2000). McGuire, Daly and Smith (2007) found a prevalence of 2.3% but said nothing further about underweight. Seven of the nine studies that compared the prevalence of underweight with the general population concluded that it was higher among adults with learning disabilities. Hove (2004a) found a higher incidence of anorexia nervosa in adults with learning disabilities than in the general population and as the definition of this condition involves underweight, this was included.

Two papers found the prevalence of underweight in adults with learning disabilities to be lower than in the general population. In Moore, McGillivray and Illingworth’s (2004) study, 6% of their sample of adults with learning disabilities were underweight, compared to 6.5% in the general population of Australia. The authors highlighted caveats about generalising from their results due to the limited sample size and specific demographics of the Adult Training Centres from which participants were recruited. More recently, Koritsas and Iacono’s (2016) study in Australia found that none (0%) of their 68 participants were underweight, compared to 2% in the general population. Unfortunately, the lack of underweight identified in their sample was not explored due to their focus on obesity. Their recruitment strategy varied between the services participating and is not outlined in detail, so it is not possible to say whether this was different from other studies and affected this finding. These two studies were of average quality, although a significant limitation of both was in not controlling for
confounding variables between the study population and the general population with whom they compared.

The seven papers that reported a higher prevalence of underweight among adults with learning disabilities (Bhaumik, Watson, Thorp, Tyler & McGrother, 2008; Eden & Randle-Phillips, 2017; Emerson, 2005; Hoey et al, 2017; Hove, 2004b; Robertson et al., 2000; Wong, 2011) included Bhaumik et al., which had the highest quality rating out of all the papers reviewed, and did control for confounding variables. However, three of these seven studies did not control for confounding variables when comparing the prevalence with the general population.

Overall, the papers reporting a higher prevalence of underweight among adults with learning disabilities were assessed as having very similar quality levels to those reporting a lower prevalence, with average quality ratings of 68% for both groups. Although more papers reported a higher prevalence than a lower prevalence, it appears that this area requires further high-quality investigation before a clear conclusion can be drawn.

Only one of the studies that compared the prevalence of underweight between adults with and without learning disabilities reported significance (Eden and Randle-Phillips, 2017), finding it to be statistically significant (p < .01). Some studies, such as Moore et al. (2004), reported that the numbers were too small to perform statistical analysis, whilst others focussed more of their findings on obesity than underweight, highlighting a limitation in these studies.
Several differences between the studies, including definitions of underweight and what and how they measured underweight made it more difficult to compare their findings. These differences will be explored further below.

The studies reviewed used four different BMI cut-offs to define underweight, including one for ‘extreme underweight’ in the context of anorexia nervosa (Hove, 2004a) (Table 4). Two studies (Emerson, 2004; Jolly & Jamieson, 1999) did not state how they defined underweight, whilst Tsai, Hsu and Chang (2011) offered an alternative cut-off point for underweight to the one they used, suggesting that the researchers were unclear on the best definition.

### Table 4: Definitions of underweight used

<table>
<thead>
<tr>
<th>Definition of underweight</th>
<th>Studies using definition</th>
<th>Prevalence of underweight in adults with learning disabilities</th>
<th>Prevalence of underweight in the general population</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI ≤ 17.5</td>
<td>Hove (2004a)</td>
<td>1.6%</td>
<td>Not reported.</td>
</tr>
<tr>
<td>BMI &lt; 18.5</td>
<td>Batista et al. (2009)</td>
<td>7%</td>
<td>Not reported.</td>
</tr>
<tr>
<td></td>
<td>Eden and Randle-Philips (2017)</td>
<td>15.4%</td>
<td>10.4%</td>
</tr>
<tr>
<td></td>
<td>Hoey et al. (2017)</td>
<td>2.4%</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td>Hove (2004b) (for adults with learning disabilities)</td>
<td>7.8%</td>
<td>See below.</td>
</tr>
<tr>
<td></td>
<td>Koritsas and Iaconoa (2016)</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td>McGuire et al. (2007)</td>
<td>2.3%</td>
<td>Not reported.</td>
</tr>
<tr>
<td></td>
<td>Moore et al. (2004)</td>
<td>6%</td>
<td>6.5%</td>
</tr>
<tr>
<td></td>
<td>Pradhan (2018)</td>
<td>1%</td>
<td>Not reported.</td>
</tr>
<tr>
<td></td>
<td>Temple et al. (2014)</td>
<td>5.5%</td>
<td>Not reported.</td>
</tr>
<tr>
<td></td>
<td>Tsai et al. (2011)</td>
<td>12.5%</td>
<td>Not reported.</td>
</tr>
<tr>
<td></td>
<td>Verstraelen et al. (2009) (in addition to FFMI below)</td>
<td>14%</td>
<td>Not reported.</td>
</tr>
<tr>
<td></td>
<td>Wong (2011)</td>
<td>25.4%</td>
<td>10.3%</td>
</tr>
<tr>
<td>BMI &lt; 20</td>
<td>Bryan et al. (2000)</td>
<td>14% then 16%</td>
<td>Not reported.</td>
</tr>
<tr>
<td></td>
<td>Emerson (2005)</td>
<td>14%</td>
<td>Total not reported (1-16% for men, 3-17% for women).</td>
</tr>
<tr>
<td></td>
<td>Hove (2004b) (for the general population)</td>
<td>See above.</td>
<td>Total not reported (3% for men, 12% for women).</td>
</tr>
<tr>
<td></td>
<td>Molteno et al. (2000)</td>
<td>29%</td>
<td>Not reported.</td>
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</table>
These different definitions of underweight (Table 4) may help to explain differences in the findings between the studies. The prevalence findings above suggest that generally, studies using a lower cut-off of BMI found the prevalence of underweight to be lower than studies using higher cut-offs. Interestingly, Hove (2004b) used a different definition of underweight in the general population compared to the definition they used for adults with learning disabilities. Using a lower cut-off for underweight in adults with learning disabilities compared to the general population may have meant that the prevalence of underweight was underestimated in adults with learning disabilities in Hove (2004b).

As well as different BMI cut-offs of underweight, some studies used different anthropometric indicators of weight status. The usefulness of BMI in people with learning disabilities has been questioned and Verstraelen et al. (2009) investigated the feasibility of different measures. They compared BMI and Fat-Free Mass Index (FFMI), finding prevalence of underweight to be 14% and 53% respectively. Unfortunately, they were unable to determine the best measure of weight status among people with learning disabilities due to limitations identified with each method, including practical difficulties with taking measurements in this population. The question therefore remains whether BMI is an appropriate measure.
There was also a difference in how weight was measured, whether it was done within the study, taken from records or reported by staff or families, or not stated. This indicates another limitation, in discrepancy in weighing procedures, process or recording, which may have contributed to the varied findings on the prevalence of underweight.

Factors associated with underweight

None of the papers looked explicitly at causes of the probable higher prevalence of underweight among adults with learning disabilities as the cross-sectional nature of the studies meant that causation could not be inferred (Moore et al., 2004). Much of the current literature focusses on demographic factors associated with underweight and seventeen of the studies reviewed explored such factors. These included male gender, younger age, severity of learning disability, accommodation type, absence of Down syndrome and not taking medication and will be explored further below. The risk and protective factors for which odds ratios were reported or could be calculated are shown in Table 5.

Table 5: Risk and protective factors for underweight

<table>
<thead>
<tr>
<th>Factors reported as significant risk factors for underweight (with Odds Ratios and 95% confidence intervals)</th>
<th>Factors reported as significant protective factors for underweight (with Odds Ratios and 95% confidence intervals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living in cluster housing OR = 1.8 (CI not reported). (Emerson, 2004)</td>
<td>Having Down syndrome OR = 0.46 (0.26-0.81). (Bhaumik et al., 2008)</td>
</tr>
<tr>
<td>Living in NHS provision OR = 2.8. (CI not reported). (Emerson, 2005)</td>
<td>Taking medication OR = 0.57 (0.38-0.87). (Bhaumik et al., 2008)</td>
</tr>
<tr>
<td>More severe learning disability</td>
<td>Being aged 30-39</td>
</tr>
</tbody>
</table>

3 For all factors identified within the Bhaumik et al. (2008) paper, odds ratios reported are those calculated using the adjusted data.
Gender

Although twelve studies (Bhaumik et al., 2008; Emerson, 2005; Hoey et al.; 2017; Hove, 2004a; Hove, 2004b; Jolly & Jamieson, 1999; Molteno et al., 2000; Moore et al., 2004; Robertson et al., 2000; Temple, Foley & Lloyd., 2014; Tsai et al., 2011; Wong, 2011) found that more male participants were underweight than female, only one of these reported that this difference was significant (Molteno et al.), and this study received a mid-range quality rating overall. Five studies did not report whether the difference was significant (Hoey et al.; Jolly & Jamieson; Temple et al.; Tsai et al.; Wong). None of the studies reported any explanation of this difference and none reported any magnitude of association for this.

Three studies (Hove, 2004b; Moore et al., 2004; Robertson et al., 2000) showed that the gender difference in underweight among adults with learning disabilities was in the opposite direction from the general population, although Hove had one of the lower quality ratings. A higher prevalence of underweight among men than women with learning disabilities but among women than men without learning disabilities suggests that the mechanisms underlying underweight may be different for adults with learning disabilities than the general population, as Hove suggested. Moore et al. argued that women with learning disabilities may be less influenced by media and peer pressure for unrealistic thinness than the general population. Alternatively, they suggested that women with learning disabilities are more satisfied with their shape and have greater

<table>
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<tr>
<th>Keyworker assigned</th>
<th>Being aged 40-49</th>
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<tbody>
<tr>
<td>OR = 2.1. (CI not reported). (Emerson, 2005)</td>
<td>OR = 0.51 (0.37-0.87). (Bhaumik et al., 2008)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Being aged 50-plus</th>
<th>OR = 0.37 (0.21-0.65). (Bhaumik et al., 2008)</th>
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</table>
wellbeing overall but did not support either of these statements with evidence. Eden and Randle-Phillips’ (2017) finding that there was not the discrepancy between perceived and ideal body shape for women (or men) with learning disabilities that they identified for women without learning disabilities could support that women with learning disabilities were more satisfied with their body shape. They also found that females with learning disabilities were likely to underestimate their body size but males were not, suggesting a possible inaccuracy in how they perceived their body size.

Interestingly, Bryan, Allen and Russell (2000) found more female participants were underweight than male participants, though did no statistical analysis to ascertain the significance of this and received a mid-range quality rating. Temple et al. (2014) identified that more women were underweight than men in the Asia-Pacific region (although more men than women were underweight in the other five regions) but again, did not report the statistical significance of this, despite being one of the higher-quality papers overall.

All of these findings must be treated with caution given that the gender difference in underweight was not significant for six of the twelve studies that reported it, and none of the studies reported any magnitudes of association.

Age

Four studies (Bhaumik et al., 2008; Emerson, 2005; Marshall, McConkey & Moore, 2003 and Wong, 2011) associated underweight with younger age. It should be noted that Marshall et al.’s participants were aged from 10 upwards and they did not specify
the ages that the statistically significant difference referred to. As shown in Table 5, Bhaumik et al.’s was the only one of these studies to report magnitudes of association for age and underweight and did so by comparing the three older age groups (30-39, 40-49 and 50-59) to the younger age group of 20-29. These odds ratios suggested that being in the three older age groups were significant protective factors for underweight when compared to the 20-29 age group. Wong also reported that the percentage of underweight decreased over 40 years of age, although increased again for the 60-79 age group. Neither study offered an explanation for this, despite Bhaumik et al. being the highest quality paper reviewed.

Accommodation

Three studies associated underweight with the type of accommodation that people lived in. Emerson (2004) concluded that participants living in cluster housing (campus-type accommodation) were significantly more likely to be underweight than those living in dispersed housing, although did not attempt to explain this. In 2005, Emerson found that adults living in accommodation defined as ‘NHS-provision’ were more likely to be underweight but again did not explore possible reasons for this and was one of the lower quality papers reviewed. Bryan et al.’s (2000) participants were more likely to be underweight after having moved to small community homes from a large learning disabilities hospital. They also did not explain this or provide magnitudes of association, simply saying that adverse nutritional changes occurred and meal provision varied, as an explanation of both weight loss and weight gain. In addition to accommodation type, Emerson (2005) explored the impact of having a keyworker, which he found to be a significant risk factor for being underweight. Again, he did not attempt to explain possible reasons for this and did not explain how he defined
keyworkers. It could be that people living in different types of accommodation were more or less likely to have a keyworker so it is difficult to separate the influence of these accommodation and keyworker factors. For all the factors identified by Emerson, magnitudes of association were reported but confidence intervals were not reported, meaning that no sense of the uncertainty around these estimates was provided.

Severity of learning disability

Three studies associated underweight with severity of learning disabilities (Bhaumik et al., 2008; Emerson, 2005; Hove, 2004b), with Hove also finding that participants who were more dependent (unable to choose their menu, prepare their food, and eat without assistance) were more likely to be underweight. None of these studies explored reasons for this and Hove did not provide magnitudes of association for their findings. In Bhaumik et al.’s study, this association ceased to be significant once the data was adjusted for age, sex, ethnicity, Down syndrome, smoking status, accommodation, skills deficits, behaviour problems, cerebral palsy, hypertension and taking medication. This suggests that it could have been mediated by these factors. Emerson also failed to provide confidence intervals for their magnitude of association, meaning that no estimate of variance was provided. In addition, Eden & Randle-Phillips (2017) and Hoey et al. (2017) acknowledged that severity of learning disability may not have been measured accurately due to considering it unnecessary to conduct IQ assessments for research. Other studies may have faced a similar dilemma without acknowledging it, suggesting that these results should be treated with caution.

If underweight is associated with accommodation or support, then the fact that most of the studies recruited participants from residential or community support services
suggests that adults with learning disabilities who were not receiving assistance from services were under-represented in these studies, as acknowledged by Koritsas and Iacono (2016), Marshall et al. (2003), Moore et al. (2004) and Wong (2011). Although some studies reported that adults with varying levels of severity of learning disability were represented, adults with more severe learning disabilities are likely to receive more support. For example, Tsai et al. (2011) reported that all the participants in their study had moderate or severe learning disabilities and Bhaumik et al. (2008) acknowledged that people with milder learning disabilities were under-represented in their study. Therefore, although severity of learning disability and type of accommodation and support have both been associated individually with underweight in these studies, they appear to be related so it is difficult to assess the individual contributions of these factors.

Eating behaviour

Hove (2004b) found that underweight was significantly associated with food refusal (p < .05) and self-induced vomiting (p < .01). They acknowledged that these could be symptoms of an underlying physical illness, although did not identify any such medical condition. They also said that these behaviours could be shaped by the environment and have different behavioural functions. As their study also associated underweight with dependence (p < .001), as outlined above, it may be that adults with learning disabilities who were dependent on others regarding food intake may have participated in these behaviours as something they were able to do in an area of their life in which they were dependent on others. These behaviours could result in weight loss and subsequently underweight, however, the relationship between these behaviours and
dependence or support was not explored in this research and none of the other studies explored eating behaviours associated with underweight.

**Absence of Down syndrome**

Bhaumik et al. (2008) found that underweight was significantly associated with absence of Down syndrome, suggesting that having Down syndrome was a significant protective factor for underweight. Having said that, they also found that individuals with Down syndrome were still over twice as likely to be underweight than the general population. Wong (2011) also identified a higher prevalence of underweight among adults without Down syndrome compared to adults with Down syndrome (28.3% and 6.6% respectively), however did not conduct a statistical analysis on this, indicating one of the limitations of this study, so it is not possible to ascertain the significance of this difference.

**Not taking medication**

Bhaumik et al. (2008) found that underweight was significantly associated with not taking medication so taking medication became a significant protective factor for underweight. Although they provided the magnitude of this association, they did not explore what might be causing this. Their definition of taking medication was limited to medication for anxiety, depression, epilepsy, behaviour problems and/or sleep problems and they did not explain why they did not consider other medications.

**Other factors**

Batista, Moreira, Rauen, Corso and Fiates (2009) looked at oral health status, however concluded that this was not associated with underweight. Pradhan (2018) found that
missing teeth and caries were significantly associated with higher BMI (p < .05) but did not explore the association between these problems and underweight.

Hove (2004a) found that individuals aged 18 to 39 years and individuals with severe learning disabilities were more likely to have anorexia nervosa, which they diagnosed using criteria of underweight and food avoidance and self-induced vomiting. This diagnosis did not include the body image disturbance that is a required symptom in the general population, increasing the importance of underweight in the diagnosis in learning disabilities. Hove identified that cerebral palsy and epilepsy were related to indices of anorexia nervosa, however did not explore this and did not report any magnitudes of association for these factors.

Unfortunately, none of the papers contributing to this theme of factors associated with underweight explored possible reasons for the associations. Hove (2004b) stated that for underweight, ‘it is not possible with the present data to indicate whether the same underlying mechanisms are at work in persons with mental retardation and the general population’ (p.15). Hove did not state what the underlying mechanisms may be for adults with learning disabilities or for the general population.

**Problems associated with underweight**

As an additional finding to the two main themes above, six articles emphasised the authors’ opinion that underweight is important. However, only two studies provided evidence for these claims from within their research. Jolly and Jamieson (1999) gave an example of a woman who began to menstruate for the first time after a high-calorie diet addressed her long-term underweight, indicating that underweight could relate to
poor menstrual functioning in this population. However, it must be acknowledged that this relates to a single case and that Jolly and Jamieson’s article received the lowest quality rating. Marshall et al. (2003) described that one underweight participant had high blood pressure, although again this is from one of the lower quality papers and related to a single participant so cannot be generalised from this. Unfortunately, neither of the studies explored these findings or related them to other evidence, possibly because the studies did not focus on underweight specifically.

Discussion

Summary of evidence

This review aimed to gather and synthesise current research evidence relating to underweight among adults with learning disabilities. From the 21 papers analysed, two themes and one additional finding emerged. The research reviewed suggested that although the prevalence of underweight in adults with learning disabilities varied due to different definitions and methods, it appeared to be more prevalent than in the general population. Different factors were associated with underweight, including younger age, male gender and accommodation type, but it was not possible to infer causation from these associations due to the cross-sectional nature of much of the research. Two studies gave examples of problems that may be associated with underweight, although the lower quality of these studies and the single case nature of this evidence means that this should be interpreted with caution.

It should be noted that for none of the papers was exploring underweight the main purpose of the research. For eight studies (Bhaumik et al., 2008; Emerson, 2005; Hoey et al., 2017; Hove, 2004b; Jolly & Jamieson, 1999, Molteno et al., 2000; Moore et al.,
2004; Temple et al., 2014), the main purpose was to explore weight, including underweight and obesity, among adults with learning disabilities. One study (Marshall et al., 2003) focused mostly on obesity and included underweight as an addition. The remaining twelve studies investigated a variety of variables, of which weight (including underweight) was one. None of the papers reviewed offered a psychological perspective of underweight. Hove’s (2004a) paper studying eating disorders such as anorexia nervosa may have been expected to explore psychological factors, however removed the more psychological criteria of disturbed body image, using only the behavioural symptoms of avoidance of food and self-induced vomiting. Gravestock (2000) reported that anorexia nervosa has been associated with bereavement in adults with learning disabilities. Although Hove (2004a) collected information about recent psychosocial stress (including bereavement) experienced by participants in their study, they appeared only to use it to diagnose psychogenic overeating or vomiting and did not explore it in relation to other eating disorders, including anorexia nervosa. Low mood has been associated with underweight in the general population (De Wit, Van Straten, Van Herten, Penninx, & Cuijpers, 2009) and with obesity in adults with learning disabilities (Mulrooney, 2014) but was not considered in the research reviewed. This lack of consideration of psychological factors in this body of literature means that the specific psychological factors involved in underweight in this population remain largely unexplored.

Limitations of the body of literature

The body of literature appraised in this review was small; although 21 papers were identified, none of these had underweight as the main focus. The quality appraisal
process highlighted several methodological limitations of the studies, which have been discussed throughout the review.

Whilst the designs appeared to be appropriate to the study aims and objectives, many of the studies did not fully meet the quality criteria for describing the objective. Although the nature of the designs meant that studies did not intend to infer causality around factors associated with underweight, the lack of exploration of these factors is a significant limitation.

In some studies (Eden & Randle-Phillips, 2017; Moore et al., 2004), the sample size was described as too small to enable full analysis of all the variables, such as ethnicity. Small sample sizes suggest a limitation on the generalisability of findings, particularly as participants were often recruited from a narrow range of settings and none of the samples included adults with learning disabilities not accessing support.

Discrepancies around three factors around weight, namely definitions of underweight, what indicator of weight was measured and how weight was measured or reported were identified. There was also discrepant operationalisation of other factors, such as how severity of learning disability was defined or assessed. Three studies used different terminology, of ‘level of understanding’ (Bhaumik et al., 2009, p.290), ‘level of adaptive behaviour’ (Emerson, 2005, p. 137) and ‘level of support needs’ (Koritsas & Iacono, 2016, p.358). Different definitions and understandings of learning disabilities may have had implications for the samples recruited, particularly as recruitment strategies also varied. These discrepancies between papers make it difficult to make comparisons across the literature base. More clarity about definitions
and procedures would support a better understanding of underweight among adults with learning disabilities.

Some of the studies collected data by proxy, often through carers. This created a risk of inaccurate information or informant bias, particularly if staff had an incentive to report things in a certain way. Eden and Randle-Philips (2017) reported that people may be subject to their own bias when assessing another’s weight and recommended training to increase awareness of biases around weight and body perception.

Some of the questionnaires used (Emerson, 2004; Emerson, 2005; Hove, 2004a) had not been validated, including for use with adults with learning disabilities, suggesting another limitation linked to the early stage of this research area.

Many of the studies that compared the sample to the general population did not control for confounding variables, such as age, gender and ethnicity. Many of these also did not provide information on ethnicity of their study sample, which makes it difficult to assess whether the samples were representative and therefore how possible it is to generalise the findings beyond the samples. Some of these potentially confounding variables were found to be associated with weight in some studies, including that younger age and male gender were associated with underweight. Eden and Randle-Phillips (2017) identified significant differences in age and ethnicity between their sample of adults with learning disabilities and the general population, however did not control for this.
A major limitation of this literature was in the reporting of findings. Only three studies (Bhaumik et al., 2009; Emerson, 2004; Emerson, 2005) reported magnitudes of association for significant associations relating to underweight and Emerson did not provide confidence intervals as an estimate of variance for their results. It was not possible to calculate magnitudes of association for the remaining papers, despite attempts to contact authors for this data. This makes it difficult to compare the associations found between studies. Additionally, five studies (Bryan et al., 2000; Hove, 2004a; Hove, 2004b; Molteno et al., 2000; Moore et al., 2004) did not provide information about variance in their findings, meaning that there was no information regarding the uncertainty of the estimates provided.

Limitations of the review

While this review has attempted to include as much of the available research (from 1998 onwards) as possible, it did not include unpublished research as it was not possible to do so in a systematic way. This creates a possibility that some studies may have been missed due to publication bias.

Although underweight was not the main focus of any of the papers reviewed, suggesting the attempts of the searches to capture these types of studies were at least partially successful, it is possible that other papers were missed that included some findings around underweight but were less explicit about this.

Despite the limitations, this review is the first study to undertake a systematic examination of the literature on underweight in adults with learning disabilities and
has presented a rigorous and comprehensive evaluation of the literature currently available in this field.

Clinical application

This review has uncovered themes that have implications for the support and wellbeing of adults with learning disabilities.

The studies suggested an increased prevalence of underweight among adults with learning disabilities compared to the general population. That six authors identified this as important, alongside Heslop et al.’s (2013) finding of a lower median age of death for people who were underweight suggests that underweight among adults with learning disabilities is likely to be problematic. It would therefore be helpful for family members, clinicians and support workers working with adults with learning disabilities to be aware of this increased risk of underweight. The increased prevalence could be related to diagnostic overshadowing, whereby physical or mental health symptoms are attributed to the learning disability rather than investigated (Day and Jancar, 1994). As an example, Hove (2004b) used a lower definition of underweight for the general population compared to adults with learning disabilities. This could suggest that underweight was considered less problematic for adults with learning disabilities so did not require noting until the weight is lower.

Although the factors found to be associated with underweight, including male gender and younger age, cannot be said to cause underweight in this population, it would be helpful for professionals working in this field to be aware of people within groups who may be particularly at risk of underweight. This may support early identification and
possibly prevention of underweight. However, this should be communicated carefully to prevent underweight from being overlooked in populations traditionally less at risk of underweight.

As there is currently little research evidence on interventions for underweight, an increased awareness of it as an area of concern in this population may support clinicians to identify and report effective ways of supporting adults with learning disabilities who are underweight.

There is currently little consensus in the research on how to understand underweight in this population. Different perspectives on underweight have implications for how it can be understood, prevented and addressed. If it is seen as a purely physical phenomenon, carers may respond by looking for medical causes, perhaps seeking advice from medical professionals. In this case, communication or emotional expression causes of underweight may be missed. Alternatively, if it is seen as only psychological, medical causes may be missed. None of the papers reviewed provided medical or psychological explanations for underweight. Anorexia nervosa is one explanation for underweight in adults with learning disabilities (Hove, 2004a) and is linked to trauma (Reyes-Rodriguez et al., 2011) and attachment difficulties (Ward et al., 2001), as per the neurodevelopmental model (Connan, Campbell, Katzman, Lightman & Treasure, 2003). Adults with learning disabilities are more likely to experience traumatic events (Mevisson & De Jongh, 2010) and also have a relatively high frequency of attachment difficulties (British Psychological Society, 2017; Schuengel, de Schipper, Sterkenburg & Kef, 2013), both of which have been linked to mental health difficulties (Martorell et al., 2009).
The responses of carers are particularly important when working with adults with learning disabilities in light of communication difficulties (Heslop et al., 2013) that may impede them from describing both physical and psychological phenomenon that may related to the underweight. The lack of research into underweight in adults with learning disabilities may lead to it not being included in care guidelines and therefore not being considered or addressed by support staff.

Future research

The clinical relevance of underweight combined with the lack of high-quality research indicates an imperative for further research to be conducted.

Many of the studies adopted a cross-sectional exploratory design, investigating factors that were associated with being underweight, possibly due to the early stage and limited nature of research in this area currently. However, the nature of this research prevents the drawing of conclusions about causality. Additionally, none of the research reviewed investigated psychological factors, such as mood, that have been associated with underweight in the general population (De Wit et al., 2009). This indicates a significant gap in the current body of research in this area, that the causes of underweight in adults with learning disabilities remain unclear and unexplored, and future research should aim to address this.

As Bhaumik et al. (2008) stated, information about prevalence of underweight in different groups might suggest that future research should focus on groups most at risk of underweight. It would be helpful to know more about why some people with
learning disabilities were more at risk of underweight in order to try and prevent it. For example, Wilson, Shuttleworth, Stancliffe and Parmenter (2012) called for more research on the interplay between gender roles and body mass in adults with learning disabilities, linking body mass to body image, social behaviour, physical activity, participation, marginalisation, and stereotyping. This may aid further understanding of the gender differences identified in some of the research in this review.

To support further research, it is important to clarify how underweight should be defined and measured, including the most appropriate indicator of underweight and clarification of the point at which underweight is harmful. This may be related to further exploration of the health consequences of underweight. Although six of the studies reviewed included the opinion of the authors that underweight was important, only two studies (Jolly & Jamieson, 1999; Marshall et al., 2003), both of which had low quality ratings, provided evidence of health problems experienced by participants who were underweight. Further research is required on how physical and psychological difficulties associated with underweight in the general population translates to this population. It would also be helpful to understand what level or severity of underweight is related to such health concerns, in order to support families, health professionals and support staff to know what weight is problematic and when to seek support.

Although some of the studies offered suggestions of how to manage underweight, only Jolly and Jamieson (1999) studied an intervention to address underweight (as well as obesity), and this study had the lowest quality rating and did not provide details on this intervention. The lack of literature on interventions to address underweight is a
significant gap in the current body of evidence. A better understanding of the causes of underweight in this population may support the development and evaluation of interventions to address it. Further research on effective interventions to address underweight collaboratively with adults with learning disabilities and with their families, support staff and health professionals is therefore required.

The reasons for the current lack of research are unclear but it appears that underweight may not be being noticed or raised as a concern. This is concerning when the potential physical and psychological consequences of underweight are considered (albeit not yet fully understood within this population), and particularly in light of the difficulties in communicating concerns experienced by many adults with learning disabilities.

Support staff, family members and health professionals all have contact with and responsibility for adults with learning disabilities and would therefore be in a good position to notice and seek support for underweight amongst the adults they support. However, no research exploring the perspectives of these groups on underweight among adults with learning disabilities was identified in this review. It would appear that this would therefore be a helpful topic for further research.

**Conclusion**

This review revealed an apparent higher prevalence of underweight for adults with learning disabilities compared to the general population. Factors associated with underweight in adults with learning disabilities were identified. Unfortunately, methodological weaknesses make it difficult to understand or address this phenomenon within the current literature base. Discrepancies in how underweight was
defined, measured and reported impeded comparisons across the studies and should be clarified in future research. Additionally, no research has explored causes or helpful interventions to address underweight in this population.

The findings of this review have implications for those supporting adults with learning disabilities, including an awareness of groups that may be at particularly high risk of underweight. This may support the identification of effective strategies for addressing underweight in this population.

Further and higher-quality research into the prevalence of underweight and factors associated with it may support the development of a biopsychosocial model of underweight in this population. This could support the development of interventions to address underweight. Exploratory qualitative research would further support understanding of this topic, particularly on how underweight is currently understood, assessed and managed by those who support this client group.
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Appendix A: Journal Author Guidelines (JIDD)

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<table>
<thead>
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<th>Study</th>
<th>Author contacted?</th>
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<th>Nature of reply</th>
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<td>N/A</td>
</tr>
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<td>Yes</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
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<td>Yes</td>
<td>Yes</td>
<td>Trust unable to trace the author.</td>
</tr>
<tr>
<td>Eden and Randle-Phillips (2017)</td>
<td>Yes but email address not recognised and no alternative contact.</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Emerson (2004)</td>
<td>Yes</td>
<td>Yes</td>
<td>Unable to provide information.</td>
</tr>
<tr>
<td>Emerson (2005)</td>
<td>Yes</td>
<td>Yes</td>
<td>Unable to provide information.</td>
</tr>
<tr>
<td>Hoey et al. (2017)</td>
<td>Yes</td>
<td>Yes</td>
<td>Unable to provide information.</td>
</tr>
<tr>
<td>Hove (2004a)</td>
<td>Yes but email address not recognised and no alternative contact.</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Hove (2004b)</td>
<td>Yes but email address not recognised and no alternative contact.</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Jolly and Jamieson (1999)</td>
<td>Yes – attempted contact through the equivalent Trust to that she worked in.</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Koritsas &amp; Iacono (2016)</td>
<td>Yes</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Marshall et al. (2003)</td>
<td>Yes</td>
<td>Yes</td>
<td>Unable to provide information.</td>
</tr>
<tr>
<td>McGuire et al. (2007)</td>
<td>Yes</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Molteno et al. (2000)</td>
<td>Yes – attempted contact through the university they were based at and the hospital at which the research was conducted.</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Moore et al. (2004)</td>
<td>Yes</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Pradhan (2018)</td>
<td>Yes</td>
<td>Yes</td>
<td>Unable to provide information.</td>
</tr>
<tr>
<td>Robertson et al. (2000)</td>
<td>Yes</td>
<td>Yes</td>
<td>Unable to provide information.</td>
</tr>
<tr>
<td>Temple et al. (2014)</td>
<td>Yes</td>
<td>Yes</td>
<td>Planned to provide available information but did not do so despite prompting.</td>
</tr>
<tr>
<td>Tsai et al. (2011)</td>
<td>Yes</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Verstraalen et al. (2009)</td>
<td>Yes but email address not recognised and no alternative contact.</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Wong (2011)</td>
<td>Yes</td>
<td>No</td>
<td>N/A</td>
</tr>
</tbody>
</table>
### Appendix C: Additional information about studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Critique</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sample&lt;br&gt;- Sample size could be larger. &lt;br&gt;- Little information about sample characteristics.</td>
</tr>
<tr>
<td></td>
<td>Findings/conclusions&lt;br&gt;- Little discussion of underweight findings in conclusion.</td>
</tr>
<tr>
<td></td>
<td>Sample&lt;br&gt;- People with higher levels of understanding were under-represented. &lt;br&gt;- Unclear how people consented to being on register, and also response rate (how many did not consent to the health check).</td>
</tr>
<tr>
<td></td>
<td>Findings&lt;br&gt;- Under-representation of participants with mild learning disabilities may have implications for weight prevalence. &lt;br&gt;- The prevalence of obesity in the general population has risen since the comparison population was measured and also since the data was collected.</td>
</tr>
<tr>
<td>Bryan et al. (2000)</td>
<td>Design/methods&lt;br&gt;- Only looked at a few areas – did not consider servicer users’ views, service user involvement in choosing or cooking meals or the variety of meals. &lt;br&gt;- Only looked at two time points – would be interesting to follow up over time. &lt;br&gt;- Tool appears to be subjective – nursing staff views. &lt;br&gt;- No acknowledgement/control of other variables that may have changed alongside move. &lt;br&gt;+ Tool has been tested for reliability and validity.</td>
</tr>
<tr>
<td></td>
<td>Sample&lt;br&gt;- Little information about sample characteristics (e.g. age/ethnicity). &lt;br&gt;- Unclear if/how participants consented to participate. &lt;br&gt;- No information about response rate. &lt;br&gt;- Sample may not be representative outside of the area/circumstances of the home. &lt;br&gt;+ Pilot completed to determine appropriate sample size.</td>
</tr>
<tr>
<td></td>
<td>Findings&lt;br&gt;- Sample not representative - may limit generalisability of findings. &lt;br&gt;- Findings are not critiqued/limitations acknowledged in the paper.</td>
</tr>
<tr>
<td>Study</td>
<td>Design/methods</td>
</tr>
<tr>
<td>------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| **Eden & Randle-Phillips (2017)** | - The order of the questions relating to body size categories was presented consistently for all participants, which could have led to an order effect.  
- Participants were all asked these questions after rating their own perceived body shape.  
- Individuals who rated themselves on the far ends of the scale were limited in their responses for perceived-ideal body discrepancy.  
**Sample**  
- Low response rate of colleges.  
- The ethnic diversity of the sample was limited.  
- The sample was too small to explore differences between people from different cultural backgrounds.  
- BMI was not matched between the groups.  
**Findings**  
- Cognitive difficulties may partially explain the extent of variance in body dissatisfaction as opposed to social influence (IQ was not controlled or investigated).  
- No significance reported for result that adults with learning disabilities tended to hold positive beliefs about their bodies. |                                                                                           |                                                                                                    |
| **Emerson (2004)**          | **Design/methods**  
- Different sampling strategies not specified explicitly.  
**Sample**  
- Response rate not stated.  
+ Sample size is relatively large.  
- Sample may not be representative of adults with learning disabilities receiving residential support.  
- Comparison with national data suggests that participants were marginally older and living in slightly smaller units.  
+ Sample included a representative proportion of men in comparison with national data.  
**Findings**  
- While the study used instruments with acceptable psychometric properties, no check was made on the reliability or validity of data collection within the study. |                                                                                           |                                                                                                    |
| **Emerson (2005)**          | **Design/methods**  
- Different sampling strategies not specified explicitly.  
- Only examined associations between a small range of predictor variables and BMI/activity.  
**Sample**  
- Response rate not stated.  
+ Sample size was quite large.  
- Sample may not be representative of adults with learning disabilities receiving residential support. |                                                                                           |                                                                                                    |
- All participants with learning disabilities were receiving supported accommodation - activity and BMI patterns/predictors may be different for people living in family homes.
- Comparison with available national data suggests that participants were marginally older and living in slightly smaller units.
+ Sample had a representative proportion of men.
- No national information was available to judge the extent to which the ethnicity of the sample was representative.

**Findings**
- While the study used instruments with acceptable psychometric properties, no check on the reliability or validity of data collection was done within the study.

<table>
<thead>
<tr>
<th>Hoey et al. (2017)</th>
<th>Design/methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Level of learning disability was reported by client, family or carer so may have been under-reported.</td>
<td></td>
</tr>
<tr>
<td>- Some information was collected by proxy, which may affect accuracy/bias.</td>
<td></td>
</tr>
</tbody>
</table>

**Sample**
- Low response rate (6.9%).
- Smaller sample than planned.

**Findings**
- Sample not representative of the population, which limits generalisability of the findings.

<table>
<thead>
<tr>
<th>Hove (2004a)</th>
<th>Design/methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Behavioural characteristics are more explicit in the DC-LD (Diagnostic Criteria for psychiatric disorders for use with adults with Learning Disabilities), which may increase false positives.</td>
<td></td>
</tr>
<tr>
<td>- Further analysis is needed, to validate the DC-LD for diagnosing eating disorders in adults with learning disabilities.</td>
<td></td>
</tr>
<tr>
<td>- Eating disorder symptoms may relate to maladaptive behaviour.</td>
<td></td>
</tr>
<tr>
<td>- Excluding variables such as body image increases the chance of false positives.</td>
<td></td>
</tr>
<tr>
<td>- It is unclear whether criteria for infants and early childhood are applicable to adults with learning disabilities.</td>
<td></td>
</tr>
<tr>
<td>- The eating disorders identified may represent adaptive skill deficiencies in eating/self-care rather than a pure form of eating disorders in the general population.</td>
<td></td>
</tr>
</tbody>
</table>

**Sample**
- No information about ethnicity of sample.
- Unclear how health workers chose residents to complete the questionnaire for.
+ Sample size appears to be sufficient for analyses.

**Findings**
- The number of individuals with a psychiatric diagnosis was lower than expected so psychiatric disorders may not have been assessed adequately. The survey was designed only to assess eating disorders. Psychiatric disorder could have been an alternative explanation to eating disorders.

<table>
<thead>
<tr>
<th>Hove (2004b)</th>
<th>Design/methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Unable to ascertain cause and effect.</td>
<td></td>
</tr>
<tr>
<td><strong>Sample</strong></td>
<td><strong>Findings</strong></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Sample may not be representative of population.</td>
<td>Sample not representative - may limit generalisability of findings.</td>
</tr>
</tbody>
</table>

**Jolly & Jamieson (1999)**

**Design/methods**
- The design was not specified.
- Unclear whether statistical analysis was attempted.
- “Nutritional problems” were not well-defined.
- The study did not explore whether nutritional problems were identified among other service users who had declined referral to a dietitian.

**Sample**
- Too small for statistical analysis?
- No information provided on ethnicity.
- Some services lack access to appropriate equipment for weighing people who cannot stand. This could have led to under-referral to the dietitian for people without BMI measurements.

**Findings**
- No information on significance of change.
- Only reported BMI change – no reference to referral reason etc.

**Koritsas & Iacono (2016)**

**Design/methods**
- Relied on disability workers’ knowledge of the person rather than objective assessments - the accuracy is questionable.
- Physical activity data were based on one question and not verified through observation.
- No statistical analysis completed.

**Sample**
- Only people with administratively defined learning disabilities (i.e. receiving services) were invited to participate.
- Unclear how managers identified suitable participants – if they needed to volunteer, may have introduced bias.
- Invitations were only sent to disability services with an online presence so participants may not have been typical of people with learning disabilities.
- No information provided on ethnicity of participants.

**Findings**
- Lack of analysis meant that information on the significance of findings was not available.
- Sample not representative – may limit generalisability of findings.

+ Some findings (e.g. physical activity data) were similar to those reported in other studies.

**Marshall et al. (2003)**

**Design/methods**
- Vague about health check and questionnaire.
- Unable to assess the weight/height of 12% of participants.
- The project did not emphasise following up clients to see if weight changes had been maintained.
- Greater attention was paid to identifying potential problems rather than improving health.

**Sample**
- Sample seems large enough for analyses.
- No information on ethnicity.
- Unclear how participants were recruited/selected.
- Health screening did not reach people with learning disabilities over 50 years of age who did not attend services. Data on weight among older participants should therefore be treated with caution.

**Findings**
- Did not define “younger population” in results.

<table>
<thead>
<tr>
<th><strong>McGuire et al. (2007)</strong></th>
<th><strong>Design/methods</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Questionnaires were completed by carers so may not be an accurate account of all the service users’ health behaviours.</td>
<td></td>
</tr>
<tr>
<td>- The questionnaire answers may be less reliable than direct observation or self-report.</td>
<td></td>
</tr>
<tr>
<td>- The questionnaire did not include how long the carer had known the service user.</td>
<td></td>
</tr>
<tr>
<td>- Only one instrument used in the study was standardised and with established psychometric validity.</td>
<td></td>
</tr>
<tr>
<td>- Did not consider confounding variables in comparison of sample with the general population.</td>
<td></td>
</tr>
</tbody>
</table>

**Sample**
- The sample size was quite small – a larger study may generate more accurate and generalisable data.

**Findings**
- Did not compare prevalence of underweight with the general population.
- Did not explore underweight, only obesity.

<table>
<thead>
<tr>
<th><strong>Molteno et al. (2000)</strong></th>
<th><strong>Design/methods</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Unable to infer causation.</td>
<td></td>
</tr>
</tbody>
</table>

**Sample**
- Participants were all from the one hospital.
- Unclear if/how consent was obtained.

**Findings**
- Link between BMI and nourishment is unclear – appeared to be used interchangeably in the findings.
- Findings are not critiqued/limitations acknowledged in the paper.

<table>
<thead>
<tr>
<th><strong>Moore et al. (2004)</strong></th>
<th><strong>Design/methods</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Unable to infer causation using this design.</td>
<td></td>
</tr>
<tr>
<td>- Percentage Body Fat calculated for males only – unclear why not women too.</td>
<td></td>
</tr>
</tbody>
</table>

**Sample**
- Low response rate (35%).
- Sample may therefore not be generalisable to the population.
- Specific demographics of the participating Adult Training Centres – results may not be generalisable.
- Limited sample size.
- Sample size was too small to allow a statistical analysis.
<table>
<thead>
<tr>
<th><strong>Design/methods</strong></th>
<th><strong>Sample</strong></th>
<th><strong>Findings</strong></th>
</tr>
</thead>
</table>
| Pradhan (2018)    | - No clear statement of purpose and aims of research.  
|                   | - Sample may not be representative as only those who were taken to health screenings by their coaches were included.  
|                   | - Low response rate of 16.6%.  
|                   | - Little description of sample characteristics (e.g. age mean and s.d. and ethnicity not reported).  
|                   | - Underweight prevalence was not explored. |
| Robertson et al. (2000) | - Questions on diet and exercise were answered by staff retrospectively so may not be accurate.  
|                   | - Differences in the physical make up of particular conditions may invalidate BMI cut-offs used with the general population.  
|                   | - Needed more detail (or reference to more detail) in describing outcome measures.  
|                   | - Random sampling may reduce bias in participants selected.  
|                   | - Only selected services considered to have “good practice”.  
|                   | - Results may not generalise outside of the settings studied (e.g. non-“good practice” services).  
|                   | - Appears to be partial control of confounding.  
|                   | - Unclear how control for confounding in comparison with general population. |
| Temple et al. (2014) | - Unable to infer causation.  
|                   | - Unclear if/how participants consented for their data to be used in this study.  
|                   | - Data from the Africa and MENA regions were combined in this study due to fewer women from these areas.  
|                   | - Conclusions about differences between world regions are limited by the varied distribution of age between regions.  
|                   | - The generalisability of the findings was limited because information about learning disabilities, co-morbidities and health conditions was not included. |
| Tsai et al. (2011) | - The MNA is a tool designed for older persons without learning disabilities.  
|                   | - Low response rate (43%).  
|                   | - Sample may not be representative. |
- Study took place in one institution, so the results may not be generalisable.
- Diverse causes of learning disabilities - the number of participants appears small when categorised according to causes.

**Findings**
- It is possible that the diversity within the group might limit the generalisability of the findings.

<table>
<thead>
<tr>
<th>Verstraelen et al. (2009)</th>
<th><strong>Design/methods</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- It was sometimes difficult to take measurements (e.g., some people were unable to stand up straight to measure height and the waist circumference, not everyone was able to lie in the correct position).</td>
<td></td>
</tr>
<tr>
<td>- Does not define feasibility – how it was determined whether or not methods were feasible.</td>
<td></td>
</tr>
<tr>
<td><strong>Sample</strong></td>
<td></td>
</tr>
<tr>
<td>- Numbers were too small to distinguish among different conditions or body shapes.</td>
<td></td>
</tr>
<tr>
<td>- The random sampling method was not described.</td>
<td></td>
</tr>
<tr>
<td><strong>Findings</strong></td>
<td></td>
</tr>
<tr>
<td>- Underweight and normal weight prevalence were combined for waist circumference and skinfold thickness so it was not possible to ascertain the prevalence of underweight using these methods.</td>
<td></td>
</tr>
<tr>
<td>- No explanation was provided for the combining of underweight and normal weight above.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wong (2011)</th>
<th><strong>Design/methods</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- No statistical analysis undertaken.</td>
<td></td>
</tr>
<tr>
<td>- Possibility of communication limitations resulting in inaccurate or missing diagnoses.</td>
<td></td>
</tr>
<tr>
<td><strong>Sample</strong></td>
<td></td>
</tr>
<tr>
<td>- May not be representative of the learning disability population of Hong Kong.</td>
<td></td>
</tr>
<tr>
<td><strong>Findings</strong></td>
<td></td>
</tr>
<tr>
<td>- Unable to determine significance of findings due to lack of statistical analysis.</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix D: Kmet quality analysis table

<table>
<thead>
<tr>
<th>Study</th>
<th>Question/objective sufficiently described?</th>
<th>Design evident &amp; appropriate?</th>
<th>Subject selection method</th>
<th>Subject/control group or IV characteristics sufficiently described?</th>
<th>If random allocation, described?</th>
<th>If blinding investigators possible, described?</th>
<th>If blinding subjects possible, described?</th>
<th>Outcome measure well defined and robust?</th>
<th>Appropriate sample size?</th>
<th>Analysis described and appropriate?</th>
<th>Estimate of variance (CI, SE) reported for main results?</th>
<th>Confounders controlled?</th>
<th>Results reported in detail?</th>
<th>Results support conclusion?</th>
<th>Total Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Batista, Moreira, Rauen, Corso and Fiates (2009)</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>N/A</td>
<td>2</td>
<td>2</td>
<td>15/20 75%</td>
</tr>
<tr>
<td>Bhaumik, Watson, Thorp, Tyrer &amp; McGrother (2008)</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>20/22 91%</td>
</tr>
<tr>
<td>Bryan et al. (2000)</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>14/22 64%</td>
</tr>
<tr>
<td>Eden and Randle-Phillips (2017)</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>16/22 73%</td>
</tr>
<tr>
<td>Emerson (2004)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>16/22 73%</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>M</td>
<td>F</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>Percentage</td>
</tr>
<tr>
<td>------------------------------</td>
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<td>------------</td>
</tr>
<tr>
<td>Emerson (2005)</td>
<td></td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12/22 = 55%</td>
</tr>
<tr>
<td>Hoey et al. (2017)</td>
<td></td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>17/22 = 77%</td>
</tr>
<tr>
<td>Hove (2004a)</td>
<td></td>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16/22 = 73%</td>
</tr>
<tr>
<td>Hove (2004b)</td>
<td></td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12/22 = 55%</td>
</tr>
<tr>
<td>Jolly and Jamieson (1999)</td>
<td></td>
<td>1</td>
<td>0</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7/14 = 50%</td>
</tr>
<tr>
<td>Koritsas &amp; Iacono (2016)</td>
<td></td>
<td>2</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10/16 = 63%</td>
</tr>
<tr>
<td>Marshall et al. (2003)</td>
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<td>Molteno, Smit, Mills and Huskisson (2000)</td>
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Part Three – Clinical experience

Overview of clinical experience

Year One:
Adult community mental health team – 1 year
In my first year, I completed a year-long placement in a community team for adults with mental health difficulties. I worked with adults aged 18-65 with severe and enduring mental health difficulties. My supervisor’s main model was cognitive behavioural therapy so this placement offered an opportunity to gain a good foundation of knowledge and skills in this model. I worked with people who had a variety of mental health diagnoses, including depression, anxiety, bipolar disorder, psychosis and obsessive-compulsive disorder, using different CBT formulation-based approaches to do so. I also co-facilitated a six-week rolling CBT-based coping skills group, supporting service users to share their experiences and develop skills from a CBT-based approach.

I developed my skills in neuropsychological assessment with people referred due to concerns about their cognitive functioning. This involved using the Wechsler Adult Intelligence Scale (WAIS) and the Wechsler Memory Scale (WMS).

I co-delivered a presentation on motivation as part of a programme of CPD presentations for staff working in the trust, which supported the development of my presentation skills.

Year Two:
Older adult community behaviour and communication support service – 6 months
In the first half of my second year, I worked in a fairly new service, supporting older adults with dementia and challenging behaviour living in the community. The main model underpinning this service was a version of the Newcastle model adapted for working with people living in the community. My supervisor’s main model was systemic so I was able to develop my skills of working systemically. I worked with adults who were mostly aged over 65 with dementia and their support systems, including family members and paid carers. I also liaised with other parts of their support networks, including GPs, District Nurses, charities and Social Services. This included experience of participating in and then chairing a network meeting.

I worked with some clients from within the care home team who also supported older adults with dementia and challenging behaviour, using the Newcastle model. This involved working closely with support staff and managers from care homes, undertaking functional assessments and developing care plans designed to reduce distress that was related to challenging behaviour. I shared formulations with staff, including in a team meeting to support their understanding of the reasoning behind the care plans and support their implementation.

I developed my skills in neuropsychological assessments, completing a variety of assessments, including the WAIS, Graded Naming Test (GNT), Hopkins Verbal Learning Test (HVLT), Trail Making Test, Controlled Oral Word Association (COWA-FAS), Repeatable Battery for the Test of Neuropsychological Status (RBANS), Test of Premorbid Functioning (ToPF) and subtests from the WMS and Behavioural Assessment of Dysexecutive Syndrome (BADS).
I developed an initial assessment template for the team and presented it at a multi-disciplinary team meeting, including answering any questions that colleagues had about it.

**Community team for adults with learning disabilities (health and Social Services) – 6 months**

In the second half of my second year, I worked in an integrated health and social care community team for adults with learning disabilities. I worked with adults aged 18-65 with a range of needs and living in a variety of settings, including at home with family members, in supported accommodation with staff and in residential placements. I appreciated the opportunity to work within a social services setting, building relationships with social workers and other colleagues working in social services. I also spent time working in the Enhanced Support Service, which supported adults with learning disabilities and challenging behaviour across the three learning disabilities teams within the trust.

The models underpinning the work I did on this placement were systemic and positive behaviour support, allowing me to develop skills working with both these models. I worked collaboratively with colleagues from within the team and outside the team, including with support staff and managers who worked with service users at home or in a residential setting. I was involved with a support team who were supporting the transition of a service user from a long-term hospital admission to a new placement, including facilitating a staff support/consultation group. I developed a positive behaviour support plan collaboratively with a service user and her support staff. I also co-facilitated a session with a service user for her support staff to express her views and consider together how her care plan could be adapted in light of these. I undertook a WAIS and Adaptive Behaviour Assessment System (ABAS), as part of my development of neuropsychological assessment skills.

I co-facilitated a Tree of Life group, with a service user with lived experience and another trainee and Clinical Psychologist, which was a valuable experience. The other trainee and I met with potential participants before the group to discuss whether they would like to attend and answer any questions they had. We invited their support staff or family members to attend and engage with the group, which culminated with a presentation of certificates of attendance.

I was able to attend meetings about a Transforming Care project that one of my supervisors was involved with and also able to visit a variety of statutory and non-statutory services working with adults with learning disabilities in the local area. I attended the local psychology away day and also a day of presentations on the link between learning disabilities and forensic services. This was particularly helpful as I undertook an assessment of risk of sexual violence with one service user I worked with.

I co-developed a service evaluation questionnaire with a Speech and Language Therapist, which could be adapted to be answered by parents as well as support staff. I also gave a presentation to the multi-disciplinary health and care team on the power-threat-meaning framework, which sparked an interesting discussion of how it related to ideas from other professions.

**Year Three:**

**Child and adolescent mental health service (tier 2) – 6 months**

For the first half of my third year, I worked in a tier 2 community child and adolescent mental health team. For many clients, this was their first experience of mental health services and I was involved in the daily triage and duty phone call process. I also undertook initial
assessments, from which decisions were made about the most appropriate source of support for the child and their family, within or outside the team, which often required multi-disciplinary discussion. Additionally, I undertook CBT with three individuals, with presentations including OCD, anxiety and Attention Deficit Disorder (ADD). I was also part of family sessions, as both first and second clinician, using a problem-solving approach as part of a brief family-based intervention.

I developed my neuropsychological assessment skills further by undertaking Wechsler Intelligence Scale for Children (WISC-V) assessments with two children for whom clinicians had concerns about their cognitive functioning. One of these involved multi-disciplinary working, including attending a team around the child meeting at the child’s school.

I was able to visit other children’s services in the trust, including the under 5s service and the youth offending team. I co-delivered a day’s training with two fellow trainees on working with young people who self-harm for staff linked to social services, including social workers, teachers and foster carers. I was also involved in an audit requested by commissioners on where gaps in services were identified following assessments of young people’s needs, in order to plan and prioritise allocation of any funds available in future.

**Adult oncology psychological support service (inpatient and community) – 6 months**

My final and specialist placement was in the family psychology team in an adult psychological support service in an oncology service, working with both outpatients and inpatients with cancer and their families around the impact of cancer on them and their families. I worked with parents with cancer who had children living with them, and sometimes parents of young adults with cancer. This involved undertaking assessments of the family’s needs and the impact of cancer with parents and then consideration of appropriate support options, for them and their children, as appropriate. For some families, I worked only with the parents, and for some, I worked with both the parents and the children. I also undertook bereavement support when the person with cancer died, sometimes jointly with my supervisor, sometimes with just the remaining parent and sometimes with the children too.

I also undertook triage telephone or face-to-face assessments for adults who had been referred to the adult psychological support service, to identify their needs and the most appropriate support. I was involved in screening referrals to the family psychology team, which sometimes involved liaising with the referrer or other professionals working with the person.

I attended the psychology team meetings and also the palliative care multidisciplinary team meetings. I worked jointly with other professions with some clients, and was also able to meet many members of the multidisciplinary team during my induction. I delivered a presentation on working with families for breast cancer nurses as part of a continuing professional development module they were undertaking.
# Part Four - Assessments

**PSYCHD CLINICAL PROGRAMME**

## TABLE OF ASSESSMENTS COMPLETED DURING TRAINING

### Year I Assessments

<table>
<thead>
<tr>
<th>ASSESSMENT</th>
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<tbody>
<tr>
<td>WAIS</td>
<td>WAIS Interpretation (online assessment)</td>
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<tr>
<td>Practice Report of Clinical Activity</td>
<td>Assessment and formulation of Clara, a female in her 50s diagnosed with anxiety and experiencing agoraphobia.</td>
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<tr>
<td>Audio Recording of Clinical Activity with Critical Appraisal</td>
<td>Audio recording and critical appraisal of a Cognitive Behavioural session for anxiety with a woman in her forties</td>
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<tr>
<td>Report of Clinical Activity N=1</td>
<td>Behavioural activation work with a female in her forties experiencing anxiety and depression.</td>
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<tr>
<td>Major Research Project Literature Survey</td>
<td>Underweight and Obesity in Adults with Learning Disabilities</td>
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<tr>
<td>Major Research Project Proposal</td>
<td>Exploring Support Staff’s Perceptions of Underweight in Adult Service Users with Learning Disabilities: A Qualitative Study</td>
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### Year II Assessments

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<td>Report of Clinical Activity</td>
<td>Systemic work with a man in his seventies with a diagnosis of vascular dementia and his wife.</td>
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<tr>
<td>PPLD Process Account</td>
<td>A reflection on personal and professional development in the context of a PPD group.</td>
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### Year III Assessments

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<td>Presentation of Clinical Activity</td>
<td>A systemic approach to working with frustration around not being heard: Jane and her systems</td>
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<tr>
<td>Major Research Project Literature Review</td>
<td>What do we know about underweight in adults with learning disabilities?</td>
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<tr>
<td>Report of Clinical Activity – Formal Assessment</td>
<td>A neuropsychological assessment of Ata, a boy attending Junior School, presenting with attentional difficulties in academic and social environments in the context of obsessive compulsive disorder symptoms and possible neurodevelopmental difficulties</td>
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