Weight Management for Adults with a Learning Disability Living in the Community


Consensus Statement

Produced by The Learning Disabilities Obesity Group (LDOG)
A task & finish group of the BDA Mental Health Group

Members of LDOG:
Burton, S., McIntosh, P., Jurs, A., Laverty, A., Macleod, M., Morrison. L. and Robinson, N.
SCHEDULE OF FIGURES ................................................................. 5
SCHEDULE OF TABLES ............................................................... 6
SCHEDULE OF GOOD PRACTICE POINTS (GPP) ....................... 6
Section 1. Introduction: ................................................................ 6
Section 2. Decision making and consent: .................................... 6
Section 3. Meeting the client’s needs: ......................................... 6
Section 4. Meeting the carer’s needs: ......................................... 8
Introduction .................................................................................. 9
  1a) Scope .................................................................................. 9
  1b) Definition of a learning disability ........................................... 10
  1c) Specialist services / extended roles ....................................... 10
  1d) Methodology ...................................................................... 11
  1e) User involvement .................................................................. 12
2.0 Decision making and consent .............................................. 13
The Functional Approach ............................................................. 14
Best interests ............................................................................. 15
Table 1 – Documents for carers (consent) ................................... 16
The Role of Advocacy .................................................................. 16
Case Study A ............................................................................. 17
Case Study B ............................................................................. 20
3. Meeting the client’s needs ..................................................... 24
  3a. Prevention ........................................................................... 24
3b. Intervention .......................................................................... 29
    Monitoring ............................................................................ 34
    Weight .................................................................................. 34
    Height ................................................................................... 34
    BMI ....................................................................................... 34
    ii. Social care, day opportunities, respite .................................. 35
    iii. Other Care Providers ...................................................... 35
4. Meeting the carer’s needs ..................................................... 36
  4a. Parents and families .............................................................. 36
  Care staff .................................................................................. 36
  Volunteers ................................................................................ 37
  Communication ........................................................................ 38
6. Glossary .................................................................................. 41
7. Authors’ Details ...................................................................... 44
References .................................................................................. 46
Executive Summary

This consensus statement is intended to inform and support the practice of dietitians who are not undertaking a specialist learning disabilities (LD) role, but within their caseload care for adults with LD who are overweight/obese. The dietitian has a key role within the multi-disciplinary team (MDT) to ensure concordance in approach for the management of nutrition-related conditions. The statement may also be a useful resource for other members of the MDT and their students.

People with LD experience a higher burden of ill health (and poorer outcomes) than the general population. According to the Disability Rights Commission (2006) they are 2½ times more likely to suffer health problems and 4 times as many die from preventable diseases. The range of health needs includes mental illness, epilepsy, an array of physical and sensory limitations (including impaired sense of touch, temperature, pain, taste and smell), dental disease, thyroid disorders, heart disease, binge-eating disorder (BED); dysphagia; under-nutrition and obesity (Carnaby, 2009; Department of Health (DH), 2009A; Wallace & Schluter, 2008; DH, 2007; Bernall, 2005; Melville et al., 2005; Hove, 2004; National Patient Safety Agency (NPSA), 2004; Bryan et al., 2000; Kennedy, 1997).

The health gains associated with good nutritional care include enhanced quality of life and improved disease outcomes (DH, 2004; Astor and Jeffreys, 2000). People with LD however, must be enabled as much as possible to make informed decisions and steps taken to ensure that this client group has access to both mainstream and specialist services as and when required.

Sixteen key questions (Appendix 1) were addressed and evidence was found to support eleven of these. Recommendations for future research can be found in the Summary & Conclusion.

The Statement contains information which the authors feel is relevant to the client group and highlights particular differences in approach from the general population for the practitioner to consider. Wherever possible, signposting is made to acknowledged gold standards of dietetic practice throughout the document and Good Practice Points (GPP) are indicated within the text. These are based on a consensus of practice agreed by the authors and relate to sections 1-4 within the statement i.e. Introduction; Decision making and consent; Meeting the client’s needs and Meeting the carer’s needs. This document will be reviewed by the BDA Mental Health Group (MHG) in 2014, or sooner should robust evidence become available which impacts on clinical practice.
Acknowledgements

The authors would like to thank the BDA MHG for Continuous Professional Development (CPD) funding. We would also like to extend our thanks to the following for their valued contribution in terms of observations and recommendations on draft documents:

BDA Members
BDA Office staff
BDA Specialist DOM UK members
BDA Specialist MHG members
Colleagues within authors’ networks
Reference group members

The authors would also like to acknowledge their respective employing organisations for their support.

And last but by no means least our clients and their carers.

“He’s worked really hard at trying to cut down on his food…it’s not easy.....and he just gave me the biggest hug of my life, lifted me off the ground and said he couldn’t wait to get back to swimming”

A parent on reporting a significant weight loss, after many months of dietetic intervention.

SCHEDULE OF FIGURES

| Figure 1 | Copy of client’s Talking Mat™ | p22 |
| Figure 2 | Health promotion group activity | p31 |
| Figure 3 | Recommendations when consulting in a 1:1 setting | p39 |
| Figure 4 | Recommendations when consulting in a group setting | p41 |
| Figure 5 | A checklist for care staff | p46 |
| Figure 6 | Networks supporting a client – an example | p48 |
**SCHEDULE OF TABLES**

| Table 1 | Documents for carers (consent) | p18 |
| Table 2 | Factors predisposing to obesity in LD | p29 |
| Table 3 | Weight gain of some commonly prescribed drugs in LD | p33 |
| Table 4 | Techniques to support behaviour change | p35 |
| Table 5 | Examples of barriers and possible solutions | p49 |

**SCHEDULE OF GOOD PRACTICE POINTS (GPP)**

NB: These GPPs are derived from a consensus of practice and are such, graded evidence level 4 (See page 94 for explanation of evidence levels). The GPPs should not be taken out of context, please refer to the relevant text within this document.

**Section 1. Introduction:**

*Nevertheless insufficient evidence should not be used as justification for the non-provision of services for people with LD (GPP).*

**Section 2. Decision making and consent:**

*In determining capacity to consent, it is essential to involve both clients and carers in the assessment and treatment process and to communicate openly (GPP).*

*Decision-making capacity is decision-specific and time-specific (GPP).*

*Wherever possible it is advisable to encourage clients to use the term ‘overweight’ but not at the expense of their comprehension (GPP).*

*It should be noted that the client with capacity is able to make ‘unwise’ decisions and have these decisions upheld (GPP).*

**Section 3. Meeting the client’s needs:**

*In such cases weight maintenance may be the best outcome, ensuring that the intake is nutritionally sound which in itself confers positive benefits such as relief from constipation, better mood and ‘feeling better’ (GPP).*

*Mencap, People First and other advocacy organisations which exist in local communities will be a good first point of contact as well as the CLDT (GPP).*

*Adaptation of group activities such as bingo where the numbers are substituted with fruit and vegetables, is a simple method of imparting healthy eating messages and*
introducing a degree of ‘healthy’ competition when using the Eatwell Plate model (FSA, 2009) (GPP).

Leaflets highlighting the obesogenic nature of the more commonly used drugs combined with key health promotion messages should be available in all clinic settings (GPP).

Though conventional weight maintenance regimes emphasise a high fibre and high fluid intake this is of critical importance in this client group (GPP).

Some clients have difficulties taking sufficient fluid. Therefore encouraging higher intakes of fruits and vegetables, with their naturally high fluid content, may be the preferred option rather than promoting too much insoluble fibre in the form of wholegrain foods (GPP).

It is important to have an appreciation and understanding of the skills base, values and belief systems of carers and to use this state of reality ‘not as a stick but a golden carrot’ for targeted and supportive training (GPP).

SIGN (2010), DOM UK (2007) and NICE guidance (2006) on obesity recommend a tripartite interactive model for effective weight management interventions (GPP):

Ask clients to say in their own words what they understand from the information you have given (GPP).

However, it is advisable that the client’s suitability to access such schemes is assessed before recommending such activity (GPP).

Standard pre-appointment processes may need to be adapted as it can be more effective and efficient to telephone the client/carer to make the appointment (GPP).

Also consider if the appointment needs to be at the beginning or end of a clinic session, to help to reduce the client’s anxiety levels (GPP).

To aid attendance, telephone and remind client/carer the working day before the appointment (GPP).

The information will also need to be in an accessible format to aid client understanding and compliance (GPP).

Where it is not possible to meet the specific needs of people with LD through adapting mainstream services then referrals to a local specialist CLDT can be considered (GPP).

Any discussion on anti-obesity medication or invasive interventions needs to be discussed fully with the client, their carers and key members from the specialist CLDT (GPP).

Experience suggests that fortnightly or monthly reviews would be the most effective, as leaving clients any longer leads to diminished interest and poor compliance (GPP).
For clients not accessing specialist equipment local arrangements may be made with advice from the GP or CLDT (GPP).

To reach an ideal BMI may be a totally unrealistic goal for such individuals though to achieve a 5 – 10% weight loss would be a pragmatic meaningful outcome (GPP).

If BMI is to be used in people with PMLD it would be more suitable for the client in these circumstances to use the lower end of the ideal (GPP).

Achieving a weight loss of between 5% and 10% would be a more appropriate, realistic and achievable goal irrespective of the degree of obesity (GPP).

If training needs for staff are identified, referral to the CLDT should be considered. Alternatively they could access available community training schemes which include within the programme aspects of choice, informed decision making and duty of care (GPP).

Section 4. Meeting the carer’s needs:

Any activity will of course need to be tailored to the preferences and abilities of the individual (GPP).

Melville and colleagues (2008) highlighted the need for carers to be trained on the principles of a healthy diet and the current national recommendations for physical activity and suggested that this could be incorporated into an induction course at beginning of employment (GPP).

Care staff should not dictate what an individual can choose but it is essential that a person with LD be given appropriate information about healthy food and the benefits so that they can make informed choices (GPP).

It is recommended that no more than 2-3 key changes be made at a time (GPP).

Any client-specific information whether healthier lifestyle guidelines, an individualised nutritional care plan and/or behavioural techniques should be cascaded (with the client’s consent) to all relevant persons involved with the client’s care as well as other members of the client’s supporting CLDT (GPP).

There are many steps where inconsistencies can occur, so having a schematic of key people involved in the health and well-being of the client is a critical factor in increasing the success of any prevention or intervention (GPP).
Introduction

1a) Scope

This professional consensus statement has been developed as a good practice guide for dietitians whose caseload includes adults with a learning disability (LD), who are living in the community and are overweight/obese. However other health and social care professionals, carers and students might also find this document useful.

The advice and guidance within this document are not applicable for people with Prader Willi Syndrome (PWS), those who have a higher level autistic spectrum disorder (ASD) such as Asperger’s or other specific learning difficulties (SpLD) such as Attention Deficit Disorder (ADD), Attention Deficit Hyperactive disorder (ADHD) dyslexia, dyscalculia, dyspraxia and speech and language delay.

Government policy is aimed at encouraging people with LD to access generic services. This means that healthcare professionals including dietitians are more likely to see people with LD in general clinics within primary and secondary care (Edwards, 2007; Sowney & Barr, 2004; Powrie, 2003). There has also been a major move away from institutionalised paternalistic care so that people with LD are enabled to live within the community supported by a variety of health and/or social care packages dictated by individual need. However the unforeseen increase in the level of obesity (which is more prevalent than the general population) as a consequence of the change in domicile is impacting on people’s health and quality of life (Melville et al., 2008; Henderson, 2008; Ito, 2006; Rimmer & Yamaki, 2006; Yamaki, 2005; Emmerson, 2005; Robertson et al., 2000).

Adults with LD are more nutritionally vulnerable than the general population for a number of reasons. These may include:
restricted income / poverty
inappropriate / poor living conditions
food ‘deserts’ – poor or limited availability in disadvantaged areas
difficulties with travel and transport
social isolation
social exclusion
limited training for healthcare staff about LD
limited nutritional knowledge of person with LD and carers
limited budgeting/cooking skills of person with LD and carers
reduced ability to understand and apply health messages, read or understand food labels
reduced ability/opportunity to make informed choices
dependence on others for food and drink adequacy and provision
dependence on others for eating and drinking

Physiological anomalies, polypharmacy, diagnostic overshadowing, multiple diagnoses and dysphagia are also common amongst this client group (DH, 2007). Additionally, people with profound and multiple learning disabilities (PMLD) are totally dependent on a range of carers, many of whom do not have the knowledge or
skills to enable them to provide a well balanced diet for their clients (Melville et al., 2009). Many decisions regarding their health and social care may need to be made in the client’s best interests.

1b) Definition of a learning disability

The definition of learning or intellectual disability includes all of the following dimensions (WHO, 1992):

A significant intellectual impairment with an intellectual quotient (IQ) more than 2 standard deviations below the general population i.e. an IQ below 70 on a recognised IQ test.

and

Deficits in social functioning or adaptive behaviour that significantly impact on how well a person’s coping skills allow for the everyday social demands which present within their own environment. (Formal psychological assessments may include the Vineland Adaptive Behaviour Scales and the AAMR Adaptive Behaviour Scales).

and

Are present before adulthood i.e. age 18years and are life-long.

There will be local variations on the above definition and it must be remembered that the use of IQ alone is not sufficient to define this population (HIW, 2007).

1c) Specialist services / extended roles

People with LD have an expectation and a right to access core services as well as specialist LD teams (DH,2009A; DH,2007B; Bamford, 2005; Learning Disabilities Advisory Group (LDAG) LDAG,2001; Scottish Executive,2000). Whether living at home, which could be parental, supported /assisted accommodation or within a residential setting, support should be available by such specialist teams who help clients live an ordinary life within their local community. The division of what is considered core and specialist is not (or indeed should not be) clear cut and robust working relationships between both teams are essential for the provision of a seamless service for this client group. The registered dietitian is pivotal to service provision. The knowledge, skills and role of the specialist dietitian within LD includes:

Advising on nutritional requirements in particular energy, as many clients present with extremes of both overweight and underweight due to complex difficulties

Having the knowledge and experience to interpret height, weight and anthropometric measurements when assessing nutritional status for this client group

Working without established guidelines or procedure in relation to LD but always within locally accepted scope of practice
Using a holistic approach to assess, problem-solve and ensure that health and social needs are met

Using appropriate health facilitation skills within the therapeutic framework
Contributing to the application of a legal framework
Identifying, referring and working in partnership with health and social care colleagues, agencies and organisations

Addressing inequalities in health and social care
Advocating both formally and informally
Using augmented/alternative communication
Working in dynamic environments and with service users who display unpredictable behaviours that challenge

1d) Methodology

Sixteen key questions were drawn up to focus the literature review (Appendix 1) undertaken between July 2009 and January 2010 on papers from the year 2000 onwards. The aim of the review was to look at the evidence supporting the assessment, monitoring, complications & ethical issues specific to adults who have LD and who were overweight/obese. The search strategy included the following databases:

- ASSIA
- CINAHL
- Cochrane Library
- Clinical Evidence
- text Elite
- Emerald Health Business Full text
- TRIP
- Ovid Database – including Medline

*(Full details of the search terms are available from the authors).*

Evidence was found to support eleven of these questions (Appendix 2). The adoption of a consistent approach to the critical appraisal of the resultant documentation contributes to the robustness of this statement. All reviewers followed the qualitative and quantitative guides to critiquing research (Ryan et al., 2007A, 2007B). The grading system for evidence based guidelines was also followed (Harbour and Miller, 2001). A cross-over system was employed in that papers were randomly allocated to 2 groups of reviewers (the authors) who independently appraised each paper. Cross-over occurred within each group to match appraisal outcomes.

Consensus of the critical appraisals was reached at a meeting in January 2010 before finalising the evidence tables in May 2010 (Appendix 2). Twenty two papers were discarded, one because of lack of objective date and the remainder as they were not relevant to people with LD (Appendix 3). Forty two papers were reviewed and graded as follows:
The literature review confirmed the authors’ perception that little robust research including evaluation of longer-term weight loss strategies had been conducted specific to the healthcare needs of this client group. Nevertheless insufficient evidence should not be used as justification for the non-provision of services for people with LD (GPP).

1e) User involvement

The Service Users Advisory Group was set up to ensure that people with LD can give their views about the services they use. Their first report ‘Nothing about us without us’ (DH, 2000) sought to re-affirm the importance of inclusion by advocating user involvement in service provision. Working in partnership with our clients should enable us to provide the best service within our resources, to meet their needs. Experiences from clients and carers have been included in the text. A range of dietetic and other health and social care professionals have been involved in the peer review of this document. In formulating this consensus statement the authors confirm they have followed the BDA Ratification Process (BDA, 2010).
2.0 Decision making and consent

This section of the consensus statement aims to give examples of issues that may arise and give guidance on how legislation is applied to people with LD. The issue of consent always needs to be obtained for dietary interventions, and when dealing with the general population consent is customarily obtained verbally. In clients with cognitive impairment, i.e. those with LD, however, the issue about capacity to consent needs to be explored fully. In determining capacity to consent, it is essential to involve both clients and carers in the assessment and treatment process and to communicate openly (GPP).

Assessments can be carried out without considering whether the client has ability to give consent to treatment, but in order to treat, the client's capacity must be determined. Determining capacity to consent must always be time and decision specific. It is important to remember that a person should not be treated as unable to make a decision unless all practicable steps to help him/her have been taken without success. This includes the use of alternative forms of communication, for example:

straightforward language
body language
eye pointing
symbolised information
signing

Also:
give extra time to process the information
try repeating the question if no response after 10 seconds

Legislation exists to provide a legal framework for decision-making on behalf of adults who lack the capacity to make specific decisions for themselves. It also provides the means for adults, with the capacity to do so, to plan ahead in the event of future incapacity.

Readers are recommended to refer to the relevant legislation pertaining to their geographical work base as legislation differs slightly between countries:

**Scotland**: The Adults with Incapacity Act (Scottish Parliament, 2000)
**England & Wales**: The Mental Capacity Act (DH, 2005)
**Northern Ireland**: Seeking Consent (Department of Health, Social Services and Public Safety (DHSSPS), 2003)

Relevant excerpts from the legislation are included here as it is core to the care for a person with LD.

The Short Reference Guide for Psychologists and Psychiatrists (BPS, 2007) is recommended as a brief summary of the main points of legislation and is a brief
guide to its implementation for clinicians. This Guide is applicable to England & Wales, and reflects the principles underpinning the Scottish Act.

The following is extracted from the Guide:

The Principles set out at the beginning of the Mental Capacity Act (MCA) guide the process of assessment and of substitute decision-making:

A person must be assumed to have capacity until it is established that s/he lacks capacity.

A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.

A person is not to be treated as unable to make a decision merely because s/he makes an unwise decision.

When decisions are made on behalf of someone who lacks capacity, they must be made in his/her ‘best interests’.

When decisions are made on behalf of someone who lacks capacity, the less restrictive alternative must be considered to attain the goal specified.

The MCA defines capacity as follows:

An adult can only be considered unable to make a particular decision if:
he or she has ‘an impairment of, or disturbance in, the functioning of the mind or brain’, whether permanent or temporary;

AND

He or she is unable to undertake any (one or more) of the following steps:

Understand the information relevant to the decision;

Retain that information (despite use of prompts); use or weigh that information as part of the process of making the decision;

Communicate the decision made (whether by talking, sign language or other means).

The Functional Approach

A functional approach must be taken. This means that someone’s ability to make a decision is determined by assessing whether they can undertake the steps above; it
is not determined by their diagnosis nor by the apparent wisdom of their decision. Decision-making capacity is decision-specific and time-specific (GPP).

Best interests

In considering what is in someone’s best interests when making a decision, the following should be taken into account:

- Whether and/or when the person is likely to regain capacity and whether the decision or the act to be undertaken can wait;
- How to encourage and optimise the participation of the person in the decision;
- The past and present wishes, feelings, beliefs, values of the person and any other relevant factors;
- Views of other relevant health, family, carer and social representatives. The decision should be perceived to be in the ‘best interest of the client and not that of the family or carers’.

The clinician should consult with paid and unpaid carers, as well as the client’s general practitioner (GP) to determine if a dietetic treatment specific or overarching certificate of incapacity has been completed. The latter has generally been put in place for people with PMLD, as many of these clients have permanent cognitive impairment. In some instances the client may have an advocate. Information on the role of advocacy is covered at the end of this section.

It is also recommended that other relevant professionals from the specialist community learning disabilities team (CLDT) are approached whose core skills include assessment for capacity (e.g. speech and language therapist (S&LT), clinical psychologist, psychiatrist, LD community nurse /care manager). In many cases the issue of capacity is generally decided by multi-disciplinary/agency working.

If a client does not have capacity to consent then first consider whether the carer, relative or social worker has legal guardianship or power of attorney which entitles them to consent on specific issues on behalf of the client.

The Scottish Act allows for application of a “Welfare Guardian”, who may be granted full or partial powers under the Act (Scottish Executive, 2000). Should there be no Welfare Guardian; the general practitioner in consultation with the team may complete an “Adults with Incapacity” form which enables treatments to take place. In emergency situations the medical person can act without consultation of the team. In Northern Ireland, those close to the incapacitated individual should be involved in the decision making process as detailed in “Seeking Consent” (DHSSPS, 2003).
In instances where there is no legal guardian the decision should be reached with consultation of all health, family, carer and social representatives. The convening of a multidisciplinary meeting is good practice to allow all to participate in decision making. This must be documented as well as any decisions made.

Table 1 lists the key documents for carers on the issue of consent.

**Table 1 – Documents for carers (consent)**

<table>
<thead>
<tr>
<th>Country</th>
<th>Title of Document</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>Caring and consent: information for carers ((NHS Scotland, 2009).</td>
</tr>
</tbody>
</table>

**The Role of Advocacy**

An advocate enables a client to get their views across. They may be a friend, family member or independently appointed following a referral to an advocacy group, services or statute. Anyone can advocate on behalf of an individual but if they are emotionally involved with the client, impartiality may not be possible. The advocate should contribute to the decision making process on the client’s behalf. However where conflict occurs it should be remembered that their views whilst listened to, have no legal status in relation to consent.

In some cases their views may conflict with others who are in the decision making process. As the client’s representative they should be included in client specific multi-disciplinary/agency meetings to discuss what is perceived to be in the client’s “best interests”.

Statutory Independent Mental Capacity Advocates (IMCAs) have undergone formal training as stipulated by the legislation under the English/Welsh Act (DH, 2005). Such training enables them to assist with decision making in the best interests of clients who cannot make decisions by themselves or with clients who have no family or friends who could be part of the joint multi-disciplinary/agency decision-making process. In Scotland a Mental Health Officer may be involved in this decision making process. In Northern Ireland family and carers involved with a particular client meet
with the relevant health and social care professionals and decide the way forward, acting in the client’s “best interests”

Ethical issues
It is essential that any concerns raised about the ethical approach of managing obesity in any adult with LD should be discussed fully at a multi-disciplinary and multi-agency meeting. Where appropriate this should include key family members and an advocate to ensure that all are working in a consistent manner to ensure that the best interests of the client are met at all times. All discussions and decisions must be fully documented.

Case Study A

Client has capacity to give consent.
A 25-year-old lady with bi-polar disorder and LD has been seen by the psychiatrist. The psychiatrist has assessed the lady as having an IQ of 55 but her social skills give the impression she is more able. However, the psychiatrist opinion is that the client can give consent if a combination of symbolised and straightforward language is used. The client’s psychiatric treatment involved commencing on Olanzapine, an anti-psychotic medicine than is known to cause excessive weight gain. As a precaution the psychiatrist has referred to the dietitian for weight reducing advice. The lady lives on her own, but each week has carer support for 10 hours over meal times. At present she has a body mass index of 35kg/m² (weight = 68kg; height = 1.4m). She regularly experiences joint pain on exertion and there is a strong family history of diabetes.

What happened in practice:
Pre-assessment

Q: Is there any additional information you need to know prior to carrying out assessment and treatment?
A: Psychiatrist and GP confirmed that the client was able to give consent. Carers, psychiatrist and LD S&LT advised that the client would require simplified information supported with the use of symbols.

Q: Do you have an appropriate approach/resource to enable the client to be involved in the decision-making process?
A: S&LT advised that the client already had experience in using Talking Mats™ - a communication aid used in assessing an individual’s understanding and for obtaining
opinions. Clients functioning at 3 information carrying words (words that carry the weight of the meaning) and above are able to use a Talking Mat™ effectively (Murphy and Cameron, 2008).

Assessment
The Talking Mat™: Key points to weight loss (see useful resources, page 63) used open questions to determine barriers facing the client to lose weight. The tool also helped gain vital information on the client’s opinions, knowledge and skills, as well as areas where she was willing to make lifestyle changes. See figure 1 for information given by the client.

Please note that the term ‘fat’ is used because this client had difficulty grasping the concept of being overweight but could identify with being fat. Wherever possible it is advisable to encourage clients to use the term ‘overweight’ but not at the expense of their comprehension (GPP).

Points considered

Q: Does your client understand the information they have been given?

A: Yes, the client’s verbal comments were reflected by her placement of the symbol on the mat. The client used the Talking Mat™ to demonstrate that she had a good support network and was actively involved in the various aspects of food provision and menu planning (see symbols placed under ‘feel good about’ column in figure 1). She enjoyed an assortment of active and sedentary activities, but needed persuasion to undertake the former otherwise she would just sit around.

Figure 1  Copy of client’s completed Talking Mat™
The client’s placement of the symbol ‘risk to health’ (of being fat) under the ‘not good’ column indicated that her concern regarding future health could be a possible motivating factor towards making lifestyle changes. Not liking ‘the way she looked’ and feeling that her ‘general health’ could be better, are other potential positive ‘reinforcers’ for this lady to lose weight.

The client recognised that low mood in the past affected her food intake, but felt her mood was better now. She also mentioned that she ate when bored:

“I eat when I’m hungry and I eat when I’m bored. I’m bored most days”

Client response to the question ‘What do you feel about the amount of food you eat?’

Q: Does your client fully understand the implication(s) of your intervention?
A: Yes, the client identified areas she was willing to make changes in and where she would require support.

Q: Does she have the ability to make an informed decision about dietary treatment?
A: Yes, psychiatric assessment has indicated ability to give consent, which is supported by the rest of the MDT team and in the client’s response to the Talking Mat™.

Q: Do you have the skills and knowledge to make this assessment of capacity?
A: Yes, this is a collaborative opinion between the dietitian, the psychiatrist and the CLDT S&LT. Also the dietitian had been trained in the use of Talking Mats™.

Q: Have you documented clearly your means of gaining consent and how the client consented to your intervention?
A: Opinions of family, carers, LD team professionals and the psychiatrist were fully documented in dietetic notes, and identified that the least restrictive option was offered. Photocopy of completed Talking Mat™ given to client with another included in dietetic/ team notes.

Treatment

Points to consider

Q: How would you progress with discussing how the client wishes to lose weight?
A: Completion of the Talking Mat™ identified areas for lifestyle changes and appropriate cross-referrals (this was the client’s means of giving consent for involvement of other health and social care professionals).
A referral was sent to social work to review her care package, as extra funding for additional carers’ hours would provide the support required to increase activities/exercises. Also the carers would be able to reinforce the decisions she’d made around lifestyle changes – an area she recognised she needed help with. A physiotherapy referral was also made to ensure any planned exercise programmes met her mobility and health needs.

The client agreed to a further appointment with the dietitian to look at portion sizes, i.e. an appropriate size of plate to limit portion sizes and provision of the Scottish Nutrition and Diet Resources Initiative (SNDRI) Exercise and Treat Chart (see useful resources, page 63) which encourages daily exercise as well as limiting foods high in fat and sugar.

As this client identified she needed support to make and keep to decisions a training session was set up for carers to identify how they could best support the client to meet treatment aims. The carers opted to monitor progress by monthly weighings undertaken at the local supermarket; use of a graphical weight chart that identified target weight loss; charting daily exercise activities and recording use of foods high in fat and sugar.

Q: Have you documented implementation of the intervention and monitored agreed outcomes?
A: Yes, all recorded in dietetic notes and client’s health action plan.

Remember:
The client may refuse dietary or other therapeutic intervention despite being aware of the complications of obesity. It should be noted that the client with capacity is able to make ‘unwise’ decisions and have these decisions upheld (GPP). It is imperative that the client’s decision to not participate is supported and documented.

---

Case Study B

Client does not have capacity to give consent

The client is a 39-year-old gentleman with PMLD and hemiplegia. He has no verbal communication and uses minimal body language. According to the clinical psychologist the client functions at less than one year of age and as such is unable to act on even 1 information carrying word (i.e. words that carry the weight of the meaning).

The client lives at home with elderly parents who have always consented to treatment on his behalf. The gentleman attends a local day centre three days a week. He is a wheelchair user, receiving physiotherapy sessions once a week at the day centre.
His main interests are music and food. He has a body mass index of 36kg/m² (weight = 97kg; height = 1.64m)
He recently had pneumonia and his left lung is compromised as a result, weight loss would help with his respiratory function.

What happened in practice:

Pre-assessment

Q: Is there any additional information you need to know prior to carrying out assessment and treatment?
A: Psychologist’s assessment ascertained that the client is unable to give consent in all areas of his wellbeing.

Q: Do the main carers/parents have the legal powers to give consent on the client’s behalf?
A: No. A multi-disciplinary/agency meeting to determine what intervention is in the client’s best interest was arranged, also to discuss the GP’s concern that the client’s weight was severely affecting his health.

Assessment

Q: How will you establish what is in the client’s best interest? Discuss:
What information the decision makers will require?
Current energy intake and weight gain trend highlighted
Aim of dietary intervention
Extent of dietary changes required
Burden versus benefit - client
Burden versus benefit - carers

A: A multi-disciplinary and multi-agency meeting, which included his parents and day care key worker, was held. At the meeting it was noted that the present dietary intake and activity regime would contribute to further weight gain. This would impact on current and future health and has the potential to impact on the feasibility of the client remaining at home. The health and social benefits of small sustained weight loss were discussed. There was some resistance from parents who felt it was unethical to restrict food as this was their son’s main area of pleasure in life. The introduction of slow, but steady change in energy content of the client’s diet, e.g., changing from full fat to semi-skimmed milk was however acceptable to the parents. It was agreed by all present that in the first instance a weight maintenance programme would be in his best interests as this would improve his quality of life and minimise his health risks, enabling him to stay in his own at home.
Q: Have you documented clearly the decision to treat?
A: Minutes of the multi-disciplinary/agency meeting circulated to all group members (including GP, and physiotherapist) for inclusion in their case notes.

Q: Can treatment now commence?
A: No, not until the legal documentation has been completed – refer to the various Acts previously mentioned. In this case the documentation was completed by the GP and a copy was included in the dietetic notes.

Treatment

Points to consider

Q: How would treatment be put in place? Discuss:

Which method(s) could be used to communicate intervention to family and carers?
What timescale is required?
How would you record client’s, carers’ and family’s views on the proposed intervention?
How would you resolve any disputes and what actions would be required?
What actions would be needed if family/carers disagree with the recommendations of the health and social care professionals?

A: Written dietary advice was provided to carers – in this instance family and day care staff – with a copy placed in dietetic notes. Low fat and low sugar food and drink options were tested with the client and all were readily accepted except for lighter hot chocolate drinks. This choice did not affect the client’s overall nutritional intake and plenty of other fluids were offered and consumed. The proposed and accepted changes were recorded in the health records and the GP informed.

The dietitian delivered training to day care staff on their duty of care to implement the dietary recommendations. It took a month to complete the training due to the number of staff involved and resulted in a consistent approach by carers. The gentleman not only maintained his weight which was the primary goal, he did manage to lose 5kg over a period of time (5% weight loss). This weight loss has been maintained a year later.

Q: Have you documented implementation of the intervention and monitored agreed outcomes?
A: Yes, dietetic intervention recorded in dietetic notes and health action plan, with copy of dietary treatment plan forwarded to the GP. Daily food plan provided to parents and day care staff. Day care staff also agreed to monitor his weight monthly as they had access to wheelchair scales. A graphical weight chart provided by the dietitian, also acted as a positive reinforce for the carers and parents.

Remember:
Clients with PMLD do not have the ability to access their own food and drink, relying on their carers to make appropriate choices. If carers consistently ignore dietary treatment plans they are failing in their duty of care. This needs to be raised initially with the keyworker, then their managers. If this needs to be taken further please contact your local CLDT for advice.
3. Meeting the client’s needs

3a. Prevention

i. Specific Needs
People with mild LD are more likely to become obese than people with more severe LD (RCN, 2006; Melville et al., 2008). Evidence indicates that people with LD tend to become overweight at an earlier age and stay overweight, whereas the general population tend to become more overweight with age (Gale et al., 2009; Bhaumik et al., 2008). There are many factors that can predispose people with LD to developing obesity including specific syndromes such as Down syndrome (Peterson et al., 2008; Henderson et al., 2007; Hawkins & Look, 2006; Chapman et al., 2005; Frey et al., 2005; Frey, 2004; Illingworth et al, 2003; Draheim et al., 2002; Beart et al., 2001; Jeffreys, 2000).

Table 2: Factors predisposing to obesity in LD

<table>
<thead>
<tr>
<th>Attitudes of carers</th>
<th>Boredom</th>
<th>Communication difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothyroidism*</td>
<td>Lack of knowledge</td>
<td>Lack of skills including literacy</td>
</tr>
<tr>
<td>Lack of power/control over own life</td>
<td>Limited access to exercise</td>
<td>Low income</td>
</tr>
<tr>
<td>Medication</td>
<td>Mental Illness</td>
<td>Misuse of food as rewards or motivators to engage in activities</td>
</tr>
<tr>
<td>Provision of poor diet</td>
<td>Poor self-esteem</td>
<td>Sedentary lifestyle/altered body composition</td>
</tr>
</tbody>
</table>

*thyroid check every 2 years in Down syndrome (Levy et al., 2006).

Levels of obesity are less prevalent in adults with PMLD but can occur. Inability to exercise is one factor, together with the consumption of excess energy, an existing lower resting metabolic rate (RMR) and small stature which can all lead to unwanted weight gain. In such cases weight maintenance may be the best outcome, ensuring that the intake is nutritionally sound which in itself confers positive benefits such as relief from constipation, better mood and ‘feeling better’ (GPP).

Abdominal obesity can be a problem in those who are fed via the gastrostomy route if energy requirements are over estimated. It is important to note that energy requirements for these individuals are often lower than for the general population of comparable weight and height (Fairclough et al., 2008).

Primary Care Health Checks have been introduced for people with LD since 2006 (2006 Wales; 2008 NI and 2009 England). Even so closer support and partnership working is still needed between primary care and the specialist CLDTs (Powrie, 2003). Health surveillance uptake has been found to be poor and thus many people with LD
are missing out on access to important and potentially life improving screening and advice (Henderson, 2008; Levy et al., 2007; Edwards, 2007; Levy et al., 2006).

Public health campaigns, leaflets and advertising which are available for the general population may not reach people with LD because the information may not be in an accessible format either as a hard copy or via the Internet. When planning any public health campaign it is important to consider how to reach all members of the locality including those with LD. McGuire and colleagues recommend that carers themselves need to be the primary target for public health measures due to their influence on client choice (McGuire et al., 2007). Mencap, People First and other advocacy organisations which exist in local communities will be a good first point of contact as well as the CLDT (GPP).

The written word even in an accessible format must not be relied upon as the best or indeed only medium for communication. Adaptation of group activities such as bingo where the numbers are substituted with fruit and vegetables, is a simple method of imparting healthy eating messages and introducing a degree of ‘healthy’ competition when using the Eatwell Plate model (FSA, 2009) (GPP).

**Fig. 2 Health promotion group activity**

“**Yes, it gives you more encouragement and you can talk to them about it- the weight and things. It’s more motivation I suppose.**”

Client’s response when asked if they would like to join an LD healthy eating group to lose weight.

As people with LD are often dependent on others to plan menus, shop for and cook their food, these significant others would be useful to target in any health promotion activity. Frequently, carers have little knowledge about healthy eating themselves, and many myths about healthy eating get passed on and become part of ‘custom and practice’ in the care setting. The role of the carers in prevention (and intervention) should not be overlooked as their own food beliefs, eating experiences and behaviours are imparted to the client which places an interesting perspective on ‘client choice’ (Smyth & Bell, 2006). Sometimes the clients are better informed on aspects of their own diets than the carers themselves:
“If I am not allowed it why is it put on my plate?”
A client’s response to food given to her by carers when she is on a weight reducing diet.

The impact of medications is often overlooked, with antipsychotic and antidepressant medications known to induce undesired and rapid weight gain (Burton et al., 2008; Khazaal et al., 2006; Birt, 2003). See table 3. It would therefore be beneficial for information to be available to the prescribers so that they are aware of the potential weight gain side effects of such medication. Leaflets highlighting the obesogenic nature of the more commonly used drugs combined with key health promotion messages should be available in all clinic settings (GPP).

“I never knew that my son’s medication could affect his weight. I have constantly felt that health professionals were blaming me for his overeating and his weight gain.

A parent’s response on receiving advice on weight gain and medications.

Medication side effects also include chronic constipation, a frequent problem for people with LD, which increases the risk of seizure activity though often goes unrecognised by carers because it is ‘normal’ for the client (Fairclough et al., 2008). Contributing factors also include poor gut motility, chronic inadequate fluid and fibre intake, chronic laxative usage and lack of physical activity. Constipation can add from 0.5 to 1.5kg of weight and needs to be taken into account when weight maintenance is being considered (Crawley, 2007).

Though conventional weight maintenance regimes emphasise a high fibre and high fluid intake this is of critical importance in this client group (GPP). Some clients have difficulties taking sufficient fluid. Therefore encouraging higher intakes of fruits and vegetables, with their naturally high fluid content, may be the preferred option rather than promoting too much insoluble fibre in the form of wholegrain foods (GPP).

ii Social Care, Day Services, Respite
Whilst providing a good range of services for people with LD, social care services can unwittingly contribute to the problems of obesity. Day services often have a disjointed approach to healthy eating, and may run their own healthy eating sessions, whilst still having a tuck shop containing a large variety of high energy snacks, and a dining room serving unhealthy meals.

‘Community involvement’ is a mantra which is rightly promoted, but more often than not results in visits to shopping centres, garden centres, supermarkets and cafes with the aim of having snacks or meals. These are often energy dense and expensive, leaving even less money for healthy meals or accessing other community activities such as swimming, bowling and so on.

Table 3: Weight Gain of some commonly prescribed drugs in LD
<table>
<thead>
<tr>
<th>Drug</th>
<th>Condition</th>
<th>Weight change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sodium Valporate</td>
<td>Bipolar / Epilepsy</td>
<td>+ 1.2 – 5.8kg</td>
</tr>
<tr>
<td>Lithium</td>
<td>Bipolar / Depression</td>
<td>+ 4kg</td>
</tr>
<tr>
<td>Clozapine</td>
<td>Schizophrenia</td>
<td>+ 4.2 – 9.9kg</td>
</tr>
<tr>
<td>Olanzapine&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Schizophrenia</td>
<td>+ 2.8 – 7.1kg</td>
</tr>
<tr>
<td>Risperidone</td>
<td>Psychoses</td>
<td>+ 2.1 – 2.3kg</td>
</tr>
<tr>
<td>Ziprasidone</td>
<td>Schizophrenia</td>
<td>- 2.7 – 3.2kg (not as effective)</td>
</tr>
<tr>
<td>Prednisolone</td>
<td>Muscle relaxant</td>
<td>+ 2kg</td>
</tr>
<tr>
<td>Nortriptyline</td>
<td>Depression</td>
<td>+ 3.7kg</td>
</tr>
<tr>
<td>Doxepin</td>
<td>Depression</td>
<td>+ 2.7kg</td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>Depression</td>
<td>+ 1.7kg</td>
</tr>
</tbody>
</table>

Adapted from Leslie et al., 2007

<sup>1</sup> After 1 year weight gain can be as much as 14kg

Respite care may be a useful opportunity for people with LD to experience different foods and to see how to eat a healthier diet. It depends, however on the quality of the service, and the number of times that respite is offered. It also relies on the respite service passing on information about their healthy eating plan to the client’s usual carers and vice versa.

### iii. Other providers

Paid carers / support workers often struggle to define their role, especially when the issue of ‘choice’ is so far reaching. Some see their role as protecting the person’s (with LD) long-term health, and so work hard to ensure healthy choices are made. Others see their role as promoting choice, and as long as they enable their client to make a choice, or their client can be seen to be making choices (healthy or unhealthy) they have fulfilled their role. The issue of ‘human rights’ is also cited, as people with capacity have the right to make unhealthy choices. Staff also need to remember, however that they have a duty of care to ensure their client’s health needs are met and should endeavour to facilitate informed choices as much as possible.

At a local level, managers of services need to be made aware of the role staff have in supporting people with LD, especially around their food choices. They should enable staff to access appropriate training as recommended by the CLDT, instead of expecting staff just to ‘know’. Support staff have the same access to TV and media advertising as the clients they support and may be equally confused by it, so they need access to clear advice – either from government sources such as ‘Change 4 Life’, primary care or their local dietitians. See also: Useful Resources on page 63.

Many carers already have the skills and knowledge to promote good eating habits and should be encouraged to share good practices within their teams. In some circumstances there may be a need to address specific issues pertaining to carers such as:

Varying levels of interest in food and exercise
Having little or no experience in planning healthy menus

Understanding that their clients do not require the same amount of food as they do and so providing smaller portions can be acceptable

Bringing their own theories and idiosyncrasies to the meal provision process

Perceiving clients as less fortunate than themselves and through guilt overfeeding the client

Perceiving clients as not having fulfilled lives and seeking to redress this in some way using food

Using ‘it’s the client’s choice’ as an excuse to provide/access less healthy food
It is important to have an appreciation and understanding of the skills base, values and belief systems of carers and to use this state of reality ‘not as a stick but a golden carrot’ for targeted and supportive training (GPP). Empowering carers is as important as empowering their clients. As well as providing information on nutrition, teaching the techniques in table 4 can help clients and carers to make positive lifestyle changes (Crawley, 2007).

Table 4 – Techniques to support behaviour change

<table>
<thead>
<tr>
<th>Technique</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability &amp; Convenience</strong></td>
<td>Chop fruit and vegetables and place them beside the client when they are watching TV or listening to music. Make sure there is always cooled tap water in the fridge at eye level, in attractive bottles. Make healthy options more accessible and visible in kitchen areas, offer at start of meal times and snack times. Only offer salt at the table if client asks for it. Encourage activity by ensuring appropriate clothing, footwear and sports equipment are easily accessible.</td>
</tr>
<tr>
<td><strong>Replacement</strong></td>
<td>Use puréed fruit as a sauce for ice cream instead of sugar based sauces. Use reduced fat cheese instead of full fat cheese. Use higher fibre white bread (or wholemeal) instead of standard white bread. Roast or oven bake part boiled potatoes using reduced fat oil spray. Reduced-fat spreads and low-sugar / sugar-free drinks. Grill or bake foods instead of frying.</td>
</tr>
<tr>
<td><strong>Fading</strong></td>
<td>If sugar is usually used in drinks, add slightly less sugar over time. Dilute squashes a little more, and offer water instead of squash when the client asks for a drink. Replace some biscuits on a plate with fruit, gradually increasing the amount of fruit over time. Reduce the salt in cooking over time.</td>
</tr>
</tbody>
</table>
Encourage people to walk to one bus stop further away on regular journeys.

Association
Link happy and fun events to healthy food choices.

Role modelling
Take part in the desired behaviour and exhibit enjoyment, positive attitude at all times.

Involvement
In menu planning and shopping.
In safe cooking such as food preparation.
Household activities such as washing, cleaning and gardening.

Adapted from Crawley, 2007

3b. Intervention

i. Specific Needs

Much of the evidence about obesity and LD describes the prevalence and the level of LD associated with obesity (Henderson, 2008; Henderson et al., 2007; Melville et al., 2005; Melville, 2008; Yamaki, 2005). Little evidence describes robust effective weight loss interventions, whether the resource is designed for the whole population and includes adapted approaches for people with LD or the resource is targeted specifically for people with LD wishing to lose weight.

Evidence that people with LD who are more independent (i.e. have fewer support hours), are more likely to be obese (Levy, 2006) is contradicted by other studies that suggest those living in supported accommodation are more likely to be overweight/obese, (Moore et al., 2004). In another study Levy and colleagues found that those people with LD who live with family have higher tendency for obesity (Levy et al., 2007).

It would seem reasonable therefore to assume that whether living with family, alone, or in supported living any weight loss intervention would essentially have to include support and motivation from carers (Hamilton et al., 2007). In addition, as a means of preventing obesity or limiting any further increases in weight, all paid carers ought to have mandatory induction training regarding implementing healthy
lifestyle choices as a routine duty of care (Melville et al., 2009). Training programmes on nutrition under the umbrella of health and social care are available throughout the UK. See: Useful Resources under training programmes, page 64).

Marshall and colleagues reported that moderate weight loss can be achieved and factors which aid success included teaching behavioural techniques, (portion sizes, eating patterns etc), involving support staff and increasing physical activity (Marshall et al., 2003). People with LD often collaborate when making decisions and this review highlighted the importance of motivated and informed carers being best placed to support weight management. Temple and colleagues found that perceptions of motivation very often differ between carers and clients with carers underestimating levels of motivation (Temple et al., 2007). This illustrates the need for an holistic approach when designing interventions.

There is some evidence that describes barriers to healthy lifestyle choices and the lack of education of people with LD and carers alike on guidelines for healthy lifestyles and how to implement them (Henderson, 2008; Edwards, 2007; Rimmer & Yamaki, 2006; Yamaki, 2005).

One review of weight loss interventions for people with LD indicated that the factors related to successful weight reduction included dietary changes, the teaching of behavioural techniques, the involvement of clients and support staff, increased physical activity and the sharing of nutritional and health information (Hamilton et al., 2007).

SIGN (2010), DOM UK (2007) and NICE guidance (2006) on obesity recommend a tripartite interactive model for effective weight management interventions (GPP):

- dietary change with a 600 kcal deficit / day
- increased levels of physical activity
- use of behavioural methods to support change in behaviour

These collective guidance documents are targeted at general populations and do not consider the needs of people with LD. Their generic nature will not automatically promote health improvements and may even increase the health inequalities experienced by this group (Aldrich et al., 2003).

Ellis and colleagues concluded that people with LD can lack the understanding of the benefits of healthy eating and physical activity and therefore have limited motivation for health improvement to embark on a weight loss intervention (Ellis et al., 2006). Interestingly this view is not supported by the following statement:

“Didn’t know backache, hip pain due to overweight. Never heard of cancer caused by overweight. Booklet may help people to decide to lose weight because don’t want any of these things”

Client’s response to audit of SNDRi symbolised diet sheet ‘Do you want to stay fat?’
Additionally a recent study piloting an adapted weight loss intervention programme specifically for adults with LD has shown positive results in the short term, with approximately 50% of participants achieving a minimum of 5% weight loss post intervention (Spanos et al., 2010). So there is evidence starting to emerge supporting the authors’ clinical experience that successful weight loss can be achieved by people with LD. On the other hand, many people with PMLD will not have the knowledge/skills of how to implement a weight loss programme to good effect. They are likely to require support workers/family present throughout an intervention to motivate, to aid understanding and to support the intervention (Hamilton et al., 2007).

It is important to remember how information is interpreted. Advice may be taken literally or choice may be limited to a suggestion given. For example, ‘you can have an occasional treat like chocolate’, could be interpreted as only chocolate is a treat, (what about pastries, cakes, biscuits?). The term ‘occasional’ is abstract and subjective so could be daily or weekly, or even hourly dependant on the client’s own understanding of the concept of time. Ask clients to say in their own words what they understand from the information you have given (GPP). Don’t be tempted to use the fact that the client can repeat what you have just said as a measure of understanding as many people with LD are often quite adept at recalling those words spoken most recently i.e. what is known as ‘recency effects’ (Kroese et al., 1998).

With regard to activity, it is reported that people with LD are less active than the general population (Hawkins & Look, 2006). Clients are often prevented from being physically active by a variety of reasons of which you need to be aware. These include financial difficulties, transport barriers, a shortage of staff, or staff/carers themselves not wanting to be physically active. Also those clients with limited mobility or those with PMLD have even less opportunity to increase their physical activity. Specialist physiotherapists from the CLDT should be involved in providing a range of active and/or passive exercises (to prevent contractures) for the client, though the impact in terms of energy expenditure of the latter will probably be minimal.

Investigate any local schemes such as Bikeability, Rebound and other fitness opportunities such as dancing and horse riding which provide inclusive opportunities for people with a range of disabilities. It is advisable however, that the client’s suitability to access such schemes be assessed before recommending such activity (GPP).
When consulting in a 1:1 setting...

⇒ Expect first appointment for getting to know the client and gaining trust.
⇒ Collect information on the client’s social and family network so you know the key people with whom to liaise i.e. care manager, social worker, day service, college, respite, sits, family, other healthcare workers currently involved.
⇒ Allow at least 30 minutes per consultation.
⇒ Keep distractions to a minimum.
⇒ Discourage accompanying person (if any) from answering for client and where possible to sit behind the client.
⇒ Use straightforward language.
⇒ Pace your delivery.
⇒ Ask open questions using no more than 2 information carrying words at a time.
⇒ Count to ten after each question (if needed) to give client time to reply.
⇒ Re-phrase questions to make sure client not just repeating your last word.
⇒ Use visual aids to reinforce the spoken word such as food models, photographs and symbols.
⇒ Limit any areas for change to a maximum of 3.
⇒ Use symbols or photographs and font 14, Arial, Comic Sans, Univers, Tahoma or Verdana in written communication.
⇒ Obtain the client’s consent to send copies of recommendations and any supporting information to care manager for distribution to day services and respite as appropriate.
⇒ Wherever possible review with same accompanying person for consistency.

Standard pre-appointment processes may need to be adapted as it can be more effective and efficient to telephone the client/carer to make the appointment (GPP). Also consider if the appointment needs to be at the beginning or end of a clinic session, to help to reduce the client’s anxiety levels (GPP). Partial booking and similar procedures can be confusing but if contacting by telephone is not feasible, use a minimum of (straightforward) words in the appointment letter. To aid attendance, telephone and remind client/carer the working day before the appointment (GPP).

Group sessions
There is some consensus that group sessions for people with LD and carers are effective (Marshall et al., 2003), as are those which incorporate increased physical activity (Chapman et al., 2008). Mainstream weight-loss group interventions can be accessed by people with LD with support from carers. However it is important that the carers take the opportunity to re-iterate the key messages and make sure the client feels part of the group. The information will also need to be in an accessible format to aid client understanding and compliance (GPP).
“No, I prefer to do it on my own. I went to one group before but I didn’t think what they were talking about was to do with me.”

Client’s response when talking about her previous attempts to lose weight by attending a mainstream group in her local community.

It is important to highlight that people with LD want to be (and should be) seen as equal citizens in their communities and wherever possible would prefer to access the same health services as everyone else (Mencap, 2004). The label ‘learning disability’ encompasses a wide range of abilities from mild to profound and it is important to ensure that choice is available. Where it is not possible to meet the specific needs of people with LD through adapting mainstream services, referrals to a local specialist CLDT can be considered (GPP). (See Appendix 4 for membership). Weight loss interventions which are available for the general population include commercial group sessions, prescribed medication and bariatric surgery. No evidence was found on any of these interventions being accessed by people with LD. Any discussion on anti-obesity medication or invasive interventions needs to be discussed fully with the client, their carers and key members from the specialist CLDT (GPP).

**Fig.4 Recommendations when consulting in a group setting.**

- Plan first session for solely getting to know the clients and gaining trust
- Limit membership to no more than 10 clients
- Encourage carers to attend although it is not necessary to exclude any clients who attend without support
- 2 people to run a session
- Allow a maximum of 2 hrs per session with a break in between.
- Keep to one theme per session
- Plan a maximum of 6 sessions with no more than 3 key themes for whole programme
- Keep distractions to a minimum
- Discourage accompanying person (if any) from answering for client.
- Use straightforward language
- Pace your delivery
- Ask open questions using no more than 2 information carrying words at a time.
- Count to ten after each question to give client time to reply
- Rephrase questions to make sure client is not just repeating your last word.
- Ask clients to repeat tasks given to them
- Use visual aids and activities such as food models, photographs and symbols to reinforce the spoken word
- Limit any areas for change in individual action plans to a maximum of 3
- Use symbols or photographs and font 14, Arial, Comic Sans, Univers, Tahoma or Verdana in written communication.
- Make sure that copies of activities, work completed and any supporting information are available in individual take home files/folders for client to share with carers
- Review
See Appendix 5 for a sample group session plan

**Monitoring**

Regular monitoring of progress is essential for clients with LD in order to sustain motivation. The carers should follow the monitoring protocol as advised by the dietitian which may include frequency of weight checks, food and fluid charts, and menu structure. Experience suggests that fortnightly or monthly reviews would be the most effective, as leaving clients any longer leads to diminished interest and poor compliance (GPP). On-going dietetic review is of course not necessary though some adjustments to the timeline in any local pathways should be considered, remembering that the first appointment may be a ‘getting to know you’ session. Once the key messages have been understood by the client/carer and actions and targets agreed, further dietetic reviews may be undertaken at the discretion of the clinician but with discharge in mind, not ongoing care.

**Weight**

Weight is commonly used to measure effectiveness. Other techniques are discussed later in the text. It is probably more practical to check weight using stand on scales but for those with poor mobility or balance problems seated or hoist scales are an alternative. For wheelchair users, wheelchair beam or platform scales can be used. It is essential that an accurate weight for the wheelchair is initially obtained taking into account attachments such as headrests and foot supports. Any changes to the wheelchair will mean that the chair will have to be reweighed. For clients not accessing specialist equipment local arrangements may be made with advice from the GP or CLDT (GPP)

**Height**

Height allows for the calculation of BMI and should be measured using a stadiometer for those clients able to stand straight. It will be more difficult to measure an accurate height for people with physical anomalies such as kyphosis and scoliosis. Alternative or surrogate markers of height such as measuring ulna length, knee height (suitable only if normal muscle mass, bone length/density attained) and supine length have been found to be inferior (even when normal muscle mass, bone length is present) to self/carer reported height if available (BAPEN,2003). Carers could be requested to measure a client’s length using a tape measure in privacy, and report back. However accuracy is not guaranteed and the resultant height must only be used as a guide.

**BMI**

Body Mass Index (BMI) is useful guide to the degree of overweight/obesity but must be treated with caution where an individual has altered body mass. To reach an ideal BMI may be a totally unrealistic goal for such individuals though to achieve a 5 – 10% weight loss would be a pragmatic and meaningful outcome (GPP).
Also BMI is not always an accurate predictor of body fat or fat distribution (SIGN, 2010). Clients with PMLD are more likely to have muscle wastage of their extremities and greater visceral adiposity and thus a greater risk of coronary heart disease (CHD) and respiratory problems (Draheim, 2006). If BMI is to be used in people with PMLD it would be more suitable for the client in these circumstances to use the lower end of the ideal (GPP).

Similarly using mid upper arm circumference (MUAC) and triceps skin fold (TSF) to measure body composition (and nutritional status) in response to a nutritional intervention may also be inappropriate (Fairclough et al., 2008). Achieving a weight loss of between 5% and 10% would be a more appropriate, realistic and achievable goal irrespective of the degree of obesity (GPP) and would confer positive health gains for the individual (SIGN, 2010; DOM UK, 2007; NICE, 2006).

ii. Social care, day opportunities, respite

Care staff/support workers are crucial to the success of implementing dietary guidelines. However they often lack the knowledge themselves to support healthy choice making, and training/education is essential for this staff group. (Melville et al., 2009). Care staff are central to the motivation and influencing of people they care for, especially around promoting choice and optimising their health from both a prevention and intervention perspective (Smyth & Bell, 2006).

People with LD access a variety of activities during the day which range from paid employment and voluntary work to day services provided by statutory or voluntary organisations. Building - based day services are becoming less the norm for people with LD, who are increasingly accessing existing community services with support workers. It is worth noting that accessing community services can be interpreted by staff as visiting cafes and coffee shops often by using transport rather than walking. Also staff may struggle to find alternative outings for people with LD such as bowling, walking groups, visiting exhibitions.

iii. Other Care Providers

Supported care is specific to each individual and can include help with shopping, budgeting, cooking or personal care.

Care providers are commissioned to provide support by social work services and are monitored through local authorities. Similar to social care, respite and day service providers, purchased care provider staff often have limited knowledge in nutritional and physical activity guidelines, (Melville et al., 2008), and will require training and support. From clinical experience, a commonly reported barrier to increasing physical activity is that opportunities are lost through staff shortages preventing support to attend activities outside the home environment. Physical activity can be perceived to be a low priority in supported living settings.

If training needs for staff are identified, referral to the CLDT should be considered. Alternatively they could access available community training schemes which include within the programme aspects of choice, informed decision making and duty of care (GPP).
4. Meeting the carer’s needs.

4a. Parents and families

If the person with LD is living in the family home, family members should work together in encouraging a healthy balanced diet and regular meal pattern. If the person with LD is in an environment where there are no set meals and all that is available are snack type foods, ready meals or takeaways, the individual will only know this type of food and be unaware of the long-term effects on general health. Family members should be discouraged from providing extra treats e.g. biscuits or crisps, thinking they are being kind or generous. A consistent supportive approach to healthy eating behaviour is important.

At home and in other settings food can be used either as a reward for good behaviour or to prevent the escalation of challenging behaviour. Food tends to be the most important thing to many in this client group and identifying a significantly meaningful alternative can be difficult.

Education around physical activity is also important and the support of the family is essential. Many clients will sit watching television or playing computer games unless prompted to exercise. They need to be given the opportunity to be more active as well as the right support. However interactive computer games that require exercise, dancing or movement whilst sitting may be useful depending on the client’s abilities. Low impact activities such as walking to the park and activity clubs in the evenings are an ideal way of increasing physical activity and particularly useful in circumstances where parents are themselves unable to participate. Any activity will of course need to be tailored to the preferences and abilities of the individual (GPP).

Care staff

As previously stated, people with LD require support and motivation from their care staff or family members to help them understand and implement any dietary or physical activity recommendations. The health knowledge and skills of care staff are therefore important factors to be considered if they are expected to provide support and motivation to people with LD. Melville and colleagues (2008) highlighted the need for care staff to be trained on the principles of a healthy diet and the current national recommendations for physical activity, and suggested that this could be incorporated into an induction course at the beginning of employment (GPP). A number of barriers have also been highlighted which prevent adults with LD from participating in physical activity (Henderson et al., 2007; Messent et al., 2000). The majority of these barriers could also be addressed via education and training.

It is important to work together to ensure that people with LD are supported to make informed choices and to understand the importance of healthy eating and regular physical activity. Care staff should be encouraged to provide a positive
influence in collaboration with others, including family members and health/social care professionals. In order to support people with LD to make good choices around food and drink it is essential that family friends and any staff supporting the client are confident themselves about what constitutes a healthy diet. Care staff should not dictate what an individual can choose but it is essential that a person with LD be given appropriate information about healthy food and the benefits so that they can make informed choices (GPP).

Fig 5 gives an example of a framework for care staff to help them make changes toward a healthy lifestyle for their clients either for prevention or specific interventions. These changes need to be introduced slowly especially if the client has behaviours which challenge and where any change in routine can be seen as a threat. It is recommended that no more than 2-3 key changes be made at a time (GPP). (NB: The behavioural techniques tabled on page 35 may also be useful for care staff).

**Fig 5  A checklist for care staff**

<table>
<thead>
<tr>
<th>Checklist for change</th>
</tr>
</thead>
<tbody>
<tr>
<td>⇒ Introduce small changes/new foods over a period of time.</td>
</tr>
<tr>
<td>⇒ Praise for even very small changes made by the client</td>
</tr>
<tr>
<td>⇒ Tasting sessions for new foods are an idea to familiarise service users with changes to menus.</td>
</tr>
<tr>
<td>⇒ Have discussion forums with service users to get their opinions.</td>
</tr>
<tr>
<td>⇒ Work and plan menus together.</td>
</tr>
<tr>
<td>⇒ Avoid confrontation – do not demonise any particular foods or drinks.</td>
</tr>
<tr>
<td>⇒ Allow less healthier foods in restricted quantities at specified times.</td>
</tr>
<tr>
<td>⇒ Avoid food as rewards if possible.</td>
</tr>
<tr>
<td>⇒ Investigate ways of increasing activity levels and make it interesting e.g. gardening projects where service users can grow fruit and vegetables then enjoy eating their produce.</td>
</tr>
</tbody>
</table>

It is however important to stress to care staff that not ‘one size fits all’ though having planned menus based on healthier eating together with a positive approach to exercise will make it easier to incorporate any individual action plans which may be needed.

**Volunteers**

Many other individuals are involved in supporting people with LD, often in a voluntary capacity e.g. staff at Gateway Clubs, self advocacy groups and even befrienders. All these individuals should have knowledge of healthy eating so they can advise clients on a healthier diet and discourage unhealthy snacking. While a great many of these clubs do provide activity sessions, the end of the social event is often rounded off with crisps and fizzy drinks.
Communication

Training in communication is vital for all carers and staff - using signs, symbols, pictures, photographs, food models and the Talking Mat™ are all useful approaches. The Speech & Language Therapist can advise on various ways of overcoming any particular communication problems.

Any client specific information whether healthier lifestyle guidelines, an individualised nutritional care plan and /or behavioural techniques should be cascaded (with the client’s consent) to all relevant persons involved with the client’s care as well as other members of the client’s supporting CLDT (GPP). The social context of health can be quite complex in its supporting systems (see Fig 6). There are many steps where inconsistencies can occur, so having a schematic of key people involved in the health and well-being of the client is a critical factor in increasing the success of any prevention or intervention (GPP).

Fig 6. Networks supporting a client – an example

* not many have a specialist dietitian as a core member

5. Summary & Conclusion

There are many barriers to effective weight management especially within the LD population. From the literature and authors’ experience, examples together with possible solutions for adults with LD, are summarised in Table 5.
Table 5 – Examples of barriers and possible solutions.

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Possible solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client access to exercise/activities.</td>
<td>Link with day services, social/support workers. Referral to LD physiotherapy for appropriate exercises. Referral to LD OT for range of local activities suitable for LD clients. Access to exercise referral programmes. Person-centred planning. Health Action Plan/Health Passport.</td>
</tr>
<tr>
<td>Client access to healthier choices</td>
<td>Training of carers. Check transport arrangements. Supported shopping. Person-centred planning.</td>
</tr>
<tr>
<td>Client access to mainstream services in primary and secondary care.</td>
<td>Carers supporting clients to attend appointments. Health professionals to institute telephone. reminders and visual appointment cards to aid compliance.</td>
</tr>
<tr>
<td>Carer obliviousness to health implications of obesity</td>
<td>Encouraging managers of provider organisations to release staff to staff training programmes. Making/adapting or purchasing appropriate resources.</td>
</tr>
<tr>
<td>Non compliance</td>
<td>Training carers. Alternative provision such as groups; shopping.</td>
</tr>
<tr>
<td>Inaccessible information</td>
<td>Appropriate use of resources in accessible format. Consult with LD S&amp; LT with referral for communication plan for client and carers.</td>
</tr>
<tr>
<td>Insufficient money</td>
<td>Involve social worker/care manager to review benefits. Also OT and support workers to devise in consultation with client a client management plan i.e. budgeting.</td>
</tr>
<tr>
<td>Too much available income</td>
<td>Involve social worker/care manager to consider financial constraints as part of ‘best interests’. Also OT and support workers to devise in consultation with client a client management plan i.e. budgeting.</td>
</tr>
<tr>
<td>Low self-esteem, Past abuse</td>
<td>Discuss with LD community nurse / clinical psychologist/psychiatrist/care manager.</td>
</tr>
<tr>
<td>Boredom</td>
<td>Day/evening classes, voluntary. Work such as vocation skills centre. Care manager/social worker to review package.</td>
</tr>
<tr>
<td>Poor cooking skills (client)</td>
<td>Referral to LD OT for cooking skills. Accessing LD/mainstream day/evening classes.</td>
</tr>
<tr>
<td>Poor cooking skills (carer)</td>
<td>Encouraging managers of provider organisations to release staff to staff training programmes.</td>
</tr>
<tr>
<td>Client disempowered by carers</td>
<td>Discuss with S&amp;LT. Use of alternative/augmentative communication to gain client’s opinions; share with consent with carers.</td>
</tr>
</tbody>
</table>

Possible areas for research include:

Specific LD weight loss interventions  
Specific LD obesity integrated care pathway  
Binge Eating Disorder  
Robust scoping and outcomes evaluation of access to generic mainstream weight loss programmes
Longer term evaluations of adapted or generic mainstream weight loss interventions and maintenance programmes
Cost/benefit analysis of weight loss interventions for LD
Relationship between obesity and environment
Design, delivery and evaluation of validated education programmes for carers
Effective communication strategies for carers

“I write ‘milk’, ‘eggs’, ‘bread’, ‘dinner’ on the shopping list, but the carers don’t get the dinners I like.”
Client who relies on carers to do his shopping but cannot spell ‘spaghetti bolognaisse’, etc.

As a profession we do need to improve our history in publishing and sharing areas of good practice. One way of overcoming this could be to have an LD good practice page on the public page of the MHG website. Dietitians could submit a précis of their work together with contact details so sharing of ideas, audits or developments could take place.

In conclusion, people who have LD present with a wide range of cognitive and physical abilities and wish to have access to services, which have long been available to the non-disabled population, in order to have an equitable quality of life (LDAG, 2001; Thompson and Pickering, 2001).

The skills challenge for any health professional is to, by observation and discussion, provide evidence – based yet flexible and practicable interventions that include and meet the aspirations and needs of each client. Participatory research (and service planning and delivery) with people with LD is essential to explore their experiences of local services and garner a more realistic picture of their health and well-being needs (DH, 2009A; DH2009B; Powrie, 2003).

It has been recognised for some time that people with LD can be informative, critical and reliable service users provided that effective interview methods are employed (Kroese et al., 1998). Closer working partnerships with primary, secondary and specialist teams, together with local advocacy groups could make inclusion a realistic objective for safeguarding health improvements for people with LD.

The National Health Services within the United Kingdom have a responsibility to commission mainstream services that, in conjunction with specialist LD services, address the health inequalities of people who have LD. Maintaining effective and longer term public health and therapeutic interventions for clients with LD is an increasing resource and intellectual challenge for dietitians whether working in specialist teams or generic core services.

The provision of services based on clearly defined work streams, objectives and core business is essential for future proofing within a modernisation framework. Adoption of the GPPs and the philosophy of inclusion, which underpins this document, may
support redesign of current nutrition & dietetic departments within existing resources, thus enabling the needs of this client group to be addressed within mainstream services.

The formulation and adoption of this consensus statement is a small step towards developing an understanding of the specific nutritional health needs of adults who have LD and who are overweight / obese.

“I don’t feel comfortable and it’s not good for my heart. It’s not easy on my own, I tried and if I lose weight it feels great.”

A client’s contribution in a group discussion on ‘food and my health’

6. Glossary

**Active exercise**: is an exercise in which the client exerts force to complete an action, e.g. walking, swimming unaided. The carer is typically a supervisor and provides little to no assistance to the client unless a problem arises, i.e. fall.

**BMI** Body mass index for relating a person's body weight to their height. BMI is a person’s weight in kilograms (kg) divided by their height in meters (m) squared.

**Contractures** An abnormal, often permanent shortening, as of muscle or scar tissue, that results in distortion or deformity, especially of a joint.

**Diagnostic overshadowing where** presenting symptoms are put down to a person’s learning disability, rather than looking for another cause.

**Dyslexia** A learning difficulty that causes problems with learning language-based skills. People have trouble with reading, writing and spelling, can also affect concentration, short term memory, maths, coordination and communication skills. Dyslexia has no reflection on intelligence more the ability to access that intelligence.

**Dyscalculia** A learning difficulty comprehending mathematics.

**Dyspraxia** A learning difficulty which affects the planning of what to do and how to do it. It is associated with problems of perception, language and thought.

**Dual diagnosis** Where a client has both mental health problems and LD. The mental health national service framework should be followed.

**GPP** Good Practice Point. Based on a consensus of best practice.

**Information carrying words** An information-carrying word is any word in a sentence that must be understood in order to follow an instruction. Here is an example ‘Give me the ball’. The person asking holds out their hand, with only a ball in front of them. The addressee does not have to understand any words, because the person has shown them what they want. This statement has no information-carrying words. If there were to be a ball and a book and the same question was repeated, the
addressee needs to know the difference between ‘ball’ and ‘book’. This has one information-carrying word level. Messages can have varying numbers of information carrying words depending how they are said and what ‘clues’ are provided.

**Health Action Plan (HAP)** A Health Action Plan is a personal plan about what a person with LD can do to keep healthy. HAPs help to make sure people get the services and support they need.

**Kyphosis** Curving of the spine that causes a bowing of the back, which leads to a hunched back or slouching posture.

**Learning Difficulty** See Specific Learning Difficulty for definition.

**Learning Disability** See page 10 in text.

**MUAC** Mid-Upper Arm Circumference. Measurement of the non-dominant *arm midway between the shoulder and the elbow; can be used as a determinant of muscle mass.

*if right handed, the non dominant arm is the left arm.

**PAL** Physical Activity Level. Total energy cost of physical activity throughout the day, expressed as a ratio of BMR. Calculated from the physical activity ratio for each activity, multiplied by the time spent in that activity. A desirable PAL for health is considered to be 1.7; the average in the UK is 1.4. Activity levels are divided into Inactive (no daily exercise); Light (some daily exercise at work or tasks around the home/garden); Moderate (6 hrs on feet or regular strenuous exercise) and Heavy (labouring job or athletes in training).

**Passive exercise** is an exercise in which the physiotherapist (or carer) exerts force on the client to complete an action, e.g. assisted range of motion (ROM) exercises. The physiotherapist is physically moving a client's body to prevent thrombosis and muscle atrophy.

**PMLD** Profound and Multiple Learning Disabilities; A person with more than one learning disability where their main learning disability is profound. All people with PMLD will have great difficulty communicating. Many will have additional sensory or physical disabilities, complex health needs or mental health difficulties.

**Polypharmacy** Use of multiple medicinal products and refers to problems that can occur when a person is taking more medications than are actually clinically needed; or even if all are clinically indicated the term is also used to describe the ‘pill burden’ when too many medications are taken. The most common results of polypharmacy are increased adverse drug reactions and drug-drug interactions. Polypharmacy is most common in people with multiple medical conditions.

**PWS** – Prader Willi Syndrome is a complex genetic disorder present from birth characterised by excessive and uncontrollable appetite for food and drink; learning disability, low muscle tone, emotional instability and immature physical development.

**RMR** Resting metabolic rate. RMR resting metabolic rate is closely related to Basal Metabolic Rate (BMR) and is the background energy required for basic metabolic
functions when lying quietly awake. It is more practical than BMR because it does not have to be measured at the time of minimal expenditure in the early hours of the morning. RMR represents 60-70% of the total daily energy expenditure after subtraction of the energy used for activity and dietary thermogenesis.

**RNI** Reference nutrient intake. The RNI is the amount of a nutrient that is enough to ensure that the needs of nearly all the group (97.5%) are being met. By definition, many within the group will need less. If an individual is consuming the RNI of a nutrient, they are unlikely to be deficient in that nutrient.

**Scoliosis** A curvature of the spine, either congenital or acquired by very poor posture, disease or muscular weakness due to certain conditions such as cerebral palsy or muscular dystrophy.

**S&LT** Speech and Language Therapist; a specialist who evaluates and treats communication disorders and swallowing problems.

**Specific Learning Difficulty (SpLD)** A lack of progression with learning to read, write and spell and/or numeracy, contrary to the expectation built up by the normal development in other areas, with evidence that the problem is severe and persistent, despite appropriate learning opportunities. (ref: [www.doncaster.gov.uk/Images/SpLD%20GUIDELINES_tcm2-53423.doc](http://www.doncaster.gov.uk/Images/SpLD%20GUIDELINES_tcm2-53423.doc))

**TSF** Triceps skinfold thickness. A measurement of subcutaneous fat taken by measuring skinfold thickness at specific sites including triceps, biceps, subscapular and ileac crest.
7. Authors’ Details

Siân Burton (Chair of LDOG).
Professional Head of Nutrition & Dietetics for Learning Disabilities.
Abertawe and Bro-Morgannwg University Health Board
Directorate of Learning Disability Services
Elm Court. Cowbridge Road. Bridgend. CF31 3SR
Sian.Burton@wales.nhs.uk

Andrea Jurs
Senior Dietitian. Learning Disability Teams for West Kent
Department of Nutrition and Dietetics
Archery House. Bow Arrow Lane
Dartford. DA2 6PB
andrea.jurs@nhs.net

Anne Laverty
Senior Dietitian. Learning Disability Team.
Rathlea House, Mountfern Complex.
8a Rugby Avenue, Coleraine
Co. Londonderry. BT52 1JL
Anne.Laverty@northerntrust.hscni.net

Pamela McIntosh
Advanced Specialist Dietitian in Learning Disabilities
Euro House
Wellgreen Stirling
FK8 2DJ
pamela.mcintosh@nhs.net

Marjory Macleod
Advanced Specialist Dietitian in Learning Disabilities
South Central Learning Disabilities Team
Forteviot, 16 Hope Terrace.
Edinburgh. EH9 2AR
Marjory.Macleod@nhsoothian.scot.nhs.uk

Linzi Morrison
Community Learning Disability Dietitian
Longdales, Kirklands Hospital
Fallside Road,
Bothwell. G71 8BB
Linzi.Morrison@lanarkshire.scot.nhs.uk
Nicola Robinson
Senior Dietitian - Learning Disability NHS Greater Glasgow and Clyde
Joint Learning Disability Team
Kirkintilloch Health Care Centre.10 Saramago Street
Kirkintilloch. Glasgow. G66 3BF
nicola.robinson@ggc.scot.nhs.uk

Reference Group
Catherine Hankey PhD
Senior Lecturer
College of Medical, Veterinary & Life Sciences Life-Course Nutrition & Health Centre
for Population & Health Sciences 4th Floor
Walton Building Glasgow Royal Infirmary. 84 Castle Street
Glasgow G4 0SF

Carolyn Penn.
Advanced clinical specialist dietitian for learning disabilities
Aneurin Bevan Health Board
Llanfrechfa Grange Hospital
Cwmbran
Torfaen. NP44 8YN

Dimitrios Spanos
Specialist Dietitian - Learning Disabilities Research assistant
Mental Health and Wellbeing
Gartnavel Royal Hospital
1055 Great Western Rd
Glasgow G12 0XH

Janet Gerrard
Learning Disability Dietitian
Oldham Community Health Service
3 Bentley Street
Chadderton.
Oldham. OL9 6NE
References


DH (2009A) *Improving the health and well being of people with learning disabilities.* London. DH.


DOM UK (2007) The dietetic weight management intervention for adults in the one to one setting – Is it time for a radical rethink? Birmingham. BDA.


HIW (2007) *How well does the NHS in Wales commission and provide specialist learning disability services for young people and adults?* Caerphilly: Health Inspectorate Wales.


Thompson, J. and Pickering, S. (Eds) (2001) *Meeting the health needs of people who have a learning disability.* Edinburgh: Baillière Tinda


**Suggested further reading**


Useful Resources

ABMU Health Board. LD booklets
http://www.wales.nhs.uk/sitesplus/863/page/41509
BDA - CED Franchise Course Introduction to Mental Health, Learning Disabilities and Eating Disorders www.bda.uk.com
BDA MHG. www.dietitiansmentalhealthgroup.org.uk
Best Interest Guidance. www.bps.org.uk
Bristol community (LD) dietitians. LD information http://www.briscomhealth.nhs.uk/bristol-learning‐difficulties
Clear. For advice & training regarding making information accessible. www.clearforall.co.uk
Color Library Collection – Food (2003), Winslow Press, Tel.: 0845 230 2777
Health Action Plans.
Health indictors for people with learning disabilities. www.pomonaproject.org/
Mencap guidelines for accessible writing available at: www.mencap.org.uk
Mental Capacity Act 2005 Short Reference Guide. www.bps.org.uk
NHS Fife My Cook Book – coloured photographs of each stage of preparation. .Tel: 01383 565354. fionamcphee@fife‐pct.scot.nhs.uk
Obesity Pathway
http://eng.mapofmedicine.com/evidence/map/obesity_in_adults1.html
Obesity Toolkit available at www.heartforum.org.uk or www.fph.org.uk.
PMLD Link (2009) Health Care. 21 (3). 64. For article on menu planning
Pocket Colour Cards – Snack time (2003), Winslow Press, Tel.: 0845 230 2777
RCN. http://www.rcn.org.uk
Ready, S. (2006) Care pathway for the management of overweight and obesity. Available at:
SNDRI (Scottish Nutrition and Dietetic Resource Initiative) www.gcal.ac.uk
Symbols www.mayer‐johnson.com
Talking Mats and weight Management. www.talkingmats.com
Training programmes:
Agored Cymru for accredited nutrition course modules available at: www.ocnwales.org.uk
Highfield Publications for nutrition and training products (currently level 2 foundation and level 3 intermediate/supervisory for nutrition) available at http://www.highfield.co.uk/products/sector/nutrition-health/
QCF (Qualifications and Credit Framework) NVQs in Health and Social Care Levels 2-3 Diplomas in Health and Social Care are aimed at individuals working with adults and children across all social care settings. The qualifications provide specialist routes for learning disabilities or dementia care. (Nutrition units in development) more information on QCF available at http://www.edexcel.com/quals/NVQ-competence-based-qcf/hsc/Pages/default.aspx
REHIS - The Royal Environmental Health Institute Scotland for accredited course modules in nutrition available at: www.rehis.com
Appendix 1

Key Questions:

Key Question 1: What is the incidence of obesity in adults with learning disability (LD) and how does it compare to the general population?

Key Question 2: What factors contribute to obesity in adults with LD? Consider medication, genetics, endocrine disorders, type and level of activity undertaken, type and level of support from carers, degree of independence, level of knowledge.

Key Question 3: What co-morbidities and complications relate to/are associated with obesity in adults with LD? (Are they any different to the general population e.g. DM?)

Key Question 4: How is the readiness to change best assessed in obese adults with LD?

Key Question 5: What combinations of interventions are most effective for weight loss in adults with LD?

Key Question 6: What is the level of knowledge and understanding of individuals delivering weight management interventions to adults with LD?

Key Question 7: What are the outcomes (lifestyle changes, altered BMI) when obese adults with LD are treated by LD dietitians compared to generalist dietitians or dietitians who have specialised in obesity?

Key Question 8: In obese adults with LD, where other interventions have failed, what is the evidence of effectiveness of Orlistat and Sibutramine?*

Key Question 9: In obese adults with LD what is the effectiveness of bariatric surgery

Key Question 10: What are the health benefits of weight loss in adults with LD?

Key Question 11: In adults with LD who have achieved weight loss, which are the most effective support interventions in promoting weight maintenance?

Key Question 12: How is obesity measured in adults with LD?

Key Question 13: What screening tools are available for adults with LD to prevent weight gain/promote weight loss?

Key Question 14: What is the prevalence of Binge Eating Disorder (BED) in obese adults with LD? Are standard obesity interventions adequate for those who have BED, or do they require additional/alternative support?

Key Question 15: What are the outcomes (lifestyle changes, altered BMI) when the dietary treatment of obese adults with LD is carried out in individual consultations.
compared to group sessions with other obese adults with LD, compared to group sessions with other obese adults?

**Key Question 16**: What are the considerations for achieving weight loss/maintenance in obese adults with LD who are enterally fed or receive nutritionally complete supplements?

**Key**: No evidence found to address these questions.

* Literature review undertaken pre January 2010 when this medication was withdrawn from use.
### Key Evidence Table: Papers relating to key questions

#### Key Question 1: What is the incidence of obesity in adults with learning disability (LD) and how does it compare to the general population?

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 1.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Draheim, C.C. (2006) Cardiovascular Disease Prevalence and risk factors of person with mental retardation. <em>Ment Retard Dev Disabil Res Rev.</em> 12, 3-12.</td>
<td>Review</td>
<td>Level 4</td>
<td>Review of literature on cardiovascular disease (CVD) prevalence in adults with mental retardation living in community settings.</td>
<td>Literature review.</td>
<td>This study provides the evidence that CVD is of major concern in adults with mental retardation, especially those who live in the community &amp; highlights current strategies used in general populations are ineffective in combatting the disease in this client group.</td>
</tr>
<tr>
<td>Emerson, E. (2005) Underweight, obesity and exercise among adults with intellectual disabilities in</td>
<td>Non-experimental study</td>
<td>Level 2-</td>
<td>1542 adults with LD.</td>
<td>Data collection from audit based reviews of supported</td>
<td>The study identified need for targeted programmes to address the issues of physical inactivity &amp; poor diet in client group. Also highlighted problem of</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gale, L., Naqvi, H. &amp; Russ, L. (2009) Asthma, smoking and BMI in adults with intellectual disabilities: a community-based survey. <em>J Intell Disabil Res.</em> 53, 787-796.</td>
<td>Cross sectional survey</td>
<td>1097 patients with learning disability, over age 16 years from 28 GP practices in Bristol PCT.</td>
<td>Data collected from medical notes in GP practices. Info on BMI only available fro 62.8% of patients.</td>
<td>Survey looked at levels of smoking &amp; raised BMI in people with learning disability who also had asthma – people with LD who have asthma are 2.6 times more likely to die from asthma than those who do not have LD. Higher BMI found in females with LD. Proportion of adults who had a BMI&gt;30 was nearly 10% higher than the general population.</td>
<td></td>
</tr>
<tr>
<td>Melville, C. A., Cooper, S. &amp; Morrison, J. (2008) The prevalence &amp; determinants of obesity in adults with intellectual disability. <em>JARID.</em> 21, 425-437.</td>
<td>Cross sectional study.</td>
<td>Adults with learning disabilities in a defined area of Glasgow.</td>
<td>Data collected &amp; compared with results from the Scottish Health Survey (general population) 2003.</td>
<td>Women with LD more likely to be obese than men. People with mild LD more likely to be obese than those with profound LD. Men &amp; women with Down Syndrome (DS) are significantly more likely to be overweight / obese than those with LD but no DS. Women living independently in a deprived area have increased likelihood of obesity but this is not the case for men. Incidence of overweight in LD population greater at an earlier age than for general population.</td>
<td></td>
</tr>
<tr>
<td>Reference</td>
<td>Methodology</td>
<td>Study Level</td>
<td>Sample Details</td>
<td>Findings</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
<td>-------------</td>
<td>----------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Moore, K., McGillivray, Illingworth, &amp; Brookhouse, (2004) An investigation into the incidence of obesity and underweight among adults with an intellectual disability in an Australian sample. <em>J Dev Disabil.</em> <strong>29</strong>, 306-318.</td>
<td>Cross sectional study</td>
<td>Level 2</td>
<td>41 females &amp; 52 males with mild to severe learning disability – relatively small sample.</td>
<td>BMI assessed &amp; results compared to general population figures. 41.4% of females were overweight and 36.6% obese (compared to 28.8% and 18.2% respectively from the general population). 30.8% of males were overweight &amp; a further 30.8% obese (compared to 45.2% &amp; 18.5% respectively for the general population). No significant difference between males &amp; females. Levels of overweight/obesity varied across living conditions with the highest prevalence being in those living in carer assisted accommodation.</td>
<td></td>
</tr>
<tr>
<td>Yamaki, K. (2005) Body weight status among adults with intellectual disability in the community. <em>Ment Retard.</em> <strong>43</strong>, 1-10.</td>
<td>Cross sectional survey</td>
<td>Level 2-</td>
<td>Adults with LD who live outside of formal services i.e. non-institutionalised.</td>
<td>Data on health status collected through personal interview. Women &amp; middle aged adults with LD reported higher rate of obesity than men and young adults with LD. Differences not generally significant. Overall, presence of obesity significantly higher in adults with LD.</td>
<td></td>
</tr>
</tbody>
</table>
### Key Question 2: What factors contribute to obesity in adults with LD? Consider medication, genetics, endocrine disorders, type and level of activity undertaken, type and level of support from carers, degree of independence, level of knowledge.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 2.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beart, s., Hawkins, D., Stenfert Kroese, B. et al. (2001). Barriers to accessing leisure opportunities for people with learning disabilities. <em>Brit J Learn Disabil.</em> <strong>29</strong>, 133-138.</td>
<td>Descriptive focus groups using semi-structured interviewing technique.</td>
<td>Level 3</td>
<td>29 adults with mild/moderate learning disability.</td>
<td>Semi-structured interviews to determine which activities they wished to access and the perceived barriers to leisure access.</td>
<td>Activities tended to be centred around day centre activities rather than pursuits carried out at home. Lack of transport and carer/friend support were identified as main barriers to accessing activities.</td>
</tr>
<tr>
<td>Chapman, M.J., Craven, M.J. &amp; Chadwick, D.D. (2005) Fighting fit: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. <em>J Intell Disabil.</em> <strong>9</strong>, 131-144.</td>
<td>Pre-/post-intervention study with a comparison group.</td>
<td>Level 2-</td>
<td>Adult learning disability. 50 in non-input group 38 in input group</td>
<td>The input group received advice from a Healthy Living Coordinator on ways of improving their diet &amp; lifestyle. The non-input group received no advice.</td>
<td>Input group showed significant weight los over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.</td>
</tr>
<tr>
<td>Draheim, C.C., Williams, D.P. &amp; McCubbin, J.A. (2002) Physical activity, dietary intake and insulin resistance syndrome in non-diabetic</td>
<td>Cohort Study</td>
<td>Level 2+</td>
<td>145 participants with mild to moderate LD.</td>
<td>Screened for hyperinsulinaemia, hypertriglyceridaemia, LDL cholesterol,</td>
<td>Positive correlation between overweight &amp; abdominal obesity and incidence of hyperinsulinaemia and other risk factors. First study of its kind &amp; gives grounds for further research into</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Title</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>Data Collection</td>
</tr>
<tr>
<td>---------</td>
<td>------</td>
<td>-------</td>
<td>--------------</td>
<td>-------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Edwards, M.</td>
<td>2007</td>
<td>Caring for patients with a learning disability. <em>Practice Nurse</em>, 17, 38-41.</td>
<td>Review article.</td>
<td>Level 4</td>
<td>n/a</td>
</tr>
</tbody>
</table>

adults with mental retardation. *Am J Ment Retard*, 105, 361-375. Hypertension & abdominal obesity. Also questionnaire looking at dietary habits & physical activity. Health behaviours, insulin resistance and CVD. Levels of obesity higher in clients with mild learning disability & in females. Reasons: poor diet, lack of physical activity & side effects of antipsychotic drugs as well as genetic conditions e.g. Down’s Syndrome. The study identified need for targeted programmes to address the issues of physical inactivity & poor diet in client group. Also highlighted problem of obesity in LD & underweight as a problem in the younger client group. Results suggest adults with MR have similar Physical activity levels (PALS) to sedentary adults without MR. Should have included a group of active adults with MR for meaningful comparison. Small sample numbers & BMI in MR group significantly higher than in other 2 groups. Usual concerns over general level of fitness, money, transport were shown to be barriers to physical activity but more importantly, lack of knowledge about the benefits of physical activity, negative support and lack of guidance from carers was a major factor.
by using data from accelerometers.


Semi-structured interviews. Level 2- 19 adults with learning disability – 84% female, 16% male, from 5 group homes. Staff recorded physical activity levels of those participating in study. Following recording done by staff, barriers to physical activity were determined. Client’s lack of understanding of the benefits of physical activity was most significant barrier with financial constraints being another major barrier. Service users were not questioned about their perspective on barriers to physical activity.


Retrospective case note review. Level 2- Adults with Down’s syndrome age 18-61 yrs. 64 in sample. Data obtained from the primary care records. The paper highlighted the need for regular health checks for individuals with Down’s syndrome. Medical problems highlighted but obesity not listed as one of them contrary to authors saying that 20% had a BMI of greater than 35.


Cross sectional survey. Level 2+ 73 participants chosen from 4 facilities offering adult training & 1 facility providing 24 hour care to people with a learning disability. The development of a nutrition & activity knowledge scale – 18 questions related to healthy eating & exercised were asked. Nutrition & Activity Knowledge Scale (NAKS) developed. Knowledge levels about nutrition appeared to be low using NAKS, but when respondents were asked about ‘good and bad foods’, they could tell researchers the answers. Showed no real understanding of nutritional reason for why a food was good or bad; usually because ‘my carer said so’.


Retrospective health record analysis. Level 2- 103 case notes of adults with intellectual disability living in 22 group homes. Healthcare records examined for data relating to weight, height, BMI, level of intellectual disability and other health related conditions. People who were obese (36.9%) and overweight (33%) displayed more frequent challenging behaviours than those of normal/underweight. A sedentary lifestyle & poor food choices linked with increased independence are cited a reasons for high rates of obesity.

Levy, J.M.; Botuck, S. & Rimmerman, Retrospective health record analysis. Level 2- 52 adults with Age, gender, race, living 70% of the individuals were overweight/obese with
<table>
<thead>
<tr>
<th>Reference</th>
<th>Methodology</th>
<th>Level</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. (2007) Examining outpatient health care utilization among adults with severe or profound intellectual disabilities living in an urban setting: A brief snap shot. <em>J Soc Work Disabil Rehab.</em> 6, 33-45.</td>
<td>Regression analysis.</td>
<td></td>
<td>Intellectual disabilities who live in New York City, who exclusively utilized a community based medical practice. Situation, level of ID, autism, cerebral palsy, sensory impairment &amp; self injurious behaviour were obtained form individuals’ most recent Developmental Disabilities Profile. A marginally higher incidence in those who lived with their family as opposed to group homes. Less medical complications were found in the group with Down’s Syndrome. Those living at home utilized less medical appointments than those living in group homes. The authors acknowledge need to decrease obesity among adults with ID in order to maintain general health &amp; more education should be offered to families &amp; carers.</td>
</tr>
<tr>
<td>McGuire, B.E., Daly, P. &amp; Smyth, F. (2007) Lifestyle and health behaviours of adults with an intellectual disability. <em>J Intell Disabil Res.</em> 51, 497-510.</td>
<td>Prospective cross sectional postal questionnaire.</td>
<td>Level 2-</td>
<td>Questionnaire sent to 250 primary carers of individuals with LD. 125 in residential settings and 125 in parental homes. Questionnaire Study results indicate good health behaviours around fat &amp; sugar intake as compared to general population but poorer activity levels and a less healthy diet overall. (Low fruit &amp; veg &amp; low unrefined CHO intake). Choice and decision making did not seem to influence health behaviours or home setting.</td>
</tr>
<tr>
<td>Marshall, D., McConkey, R. &amp; Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. <em>J Adv Nurs.</em> 41, 147-153.</td>
<td>Pilot/observational study.</td>
<td>Level 2-</td>
<td>Study 1: sample – 464 aged 10+ - individuals with LD attending special schools &amp; day centres. Study 2: sample 25 – adults in day centres. Study 1: Health screening – 200 were referred on to their GP with various problems. Study 2: individuals were involved in group sessions where support &amp; advice was given on healthy diet &amp; lifestyle. Weight loss was greater among those attending the group sessions compared with those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers &amp; people with a LD to be actively involved in deciding on a healthy diet &amp; becoming involved in suitable exercise regimes.</td>
</tr>
<tr>
<td>Melville, C.A., Cooper, S-A., McGrother, C.W., Thorp, C.F. &amp; Collacott, R. (2005) Obesity in adults with Down Syndrome: a case control study. <em>J Intell Disabil Res.</em> 49, 125-133.</td>
<td>Case control study</td>
<td>Level 2+</td>
<td>247 matched pairs of adults with Down Syndrome (DS) &amp; those without DS but with intellectual disability. Height, weight &amp; BMI measured in order to compare the two groups and determine the incidence of overweight/obesity. Results showed that women with DS were more likely to be overweight/obese than non-DS women and men with DS were more likely to be overweight but not obese compared with non-DS. It was noted that non-DS group had higher incidence of underweight.</td>
</tr>
<tr>
<td>Reference</td>
<td>Methodology</td>
<td>Level</td>
<td>Participants</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
<td>-------</td>
<td>--------------</td>
</tr>
<tr>
<td>Messent, P.R., Cooke, C.B. &amp; Long, J. (2000)</td>
<td>Structured in-depth interviews.</td>
<td>Level 2+</td>
<td>24 adults with mild to moderate learning disability. Residential managers &amp; carers also helped with interviews.</td>
</tr>
<tr>
<td>Peterson, J.J., Janz, K.F. &amp; Lowe, J.B. (2008)</td>
<td>Objective study.</td>
<td>Level 2-</td>
<td>131 adults with mild or moderate ID living in community based supported living.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Level</td>
<td>Sample</td>
</tr>
<tr>
<td>-------</td>
<td>--------</td>
<td>-------</td>
<td>--------</td>
</tr>
<tr>
<td>Temple, V.A. &amp; Walkley, J.W. (2007). Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability. <em>J Intell Dev Disabil.</em> <strong>32</strong>, 28-38.</td>
<td>Qualitative focus groups.</td>
<td>Level 3</td>
<td>Adults with intellectual disability (n=9), direct care workers (n=5), home supervisors (n=15 total), managers (n=4) and parents (n=7).</td>
</tr>
</tbody>
</table>
**Key Question 3:** What co-morbidities and complications relate to/are associated with obesity in adults with LD? (Are they any different to the general population e.g. DM?)

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 3.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapman, M.J., Craven, M.J. &amp; Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. <em>J Intell Disabil</em>. <strong>9</strong>, 131-144.</td>
<td>Pre-/post-intervention study with a comparison group.</td>
<td>Level 2-</td>
<td>Adult learning disability. 50 in non-input group 38 in input group</td>
<td>The input group received advice from a Healthy Living Coordinator on ways of improving their diet &amp; lifestyle. The non-input group received no advice.</td>
<td>Input group showed significant weight loss over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.</td>
</tr>
<tr>
<td>Edwards, M.(2007) Caring for patients with a learning disability. <em>Practice</em></td>
<td>Review article.</td>
<td>Level 4</td>
<td>n/a</td>
<td>n/a</td>
<td>Respiratory disease cited as most common cause of</td>
</tr>
<tr>
<td>Nurse, 17, 38-41.</td>
<td>Henderson (2008) Overweight status, obesity and risk factors for coronary heart disease in adults with intellectual disability. <em>J. of Policy and Practice in Intellectual Disabilities</em>. 5, 174-177.</td>
<td>Mixed methodologies – retrospective case record in 2005 &amp; comparison with data collected in 2001.</td>
<td>Level 2-</td>
<td>100 adults with ID &amp; 2526 non-ID.</td>
<td>Data collected from medical records over 4 month period in 2005. Age, height, weight, BP, CHD risk factors were recorded. For comparison, data from a country wide adult health survey in 2000-01 were used.</td>
</tr>
<tr>
<td>Marshall, D., McConkey, R. &amp; Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. J Adv Nurs. 41, 147-153.</td>
<td>Observational study.</td>
<td>Level 2-</td>
<td>Study 1 : sample – 464 aged 10+ - individuals with LD attending special schools &amp; day centres. Study 2 : sample 25 – adults in day centres.</td>
<td>Study 1 : Health screening – 200 were referred on to their GP with various problems. Study 2 : individuals were involved in group sessions where support &amp; advice was given on healthy diet &amp; lifestyle.</td>
<td>Weight loss was greater among those attending the group sessions compared with those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers &amp; people with a LD to be actively involved in deciding on a healthy diet &amp; becoming involved in suitable exercise regimes.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Stanish, H. &amp; Draheim, C.C. (2007) Walking activity, body composition and blood pressure in adults with intellectual disabilities. J Appl Res Intell Disabil. 30, 183-190.</td>
<td>Experimental cohort study.</td>
<td>Level 2+</td>
<td>103 adults with ID aged 19-65 years.</td>
<td>Research looks at benefit of walking in individuals with intellectual disability &amp; whether this population group is reaching the target of 10,000 steps/day. Examines health benefits of walking, measuring body composition &amp; BP.</td>
<td>The interesting finding was that the ones who did achieve 10,000 steps or more/day did not display the health benefits of improved body composition and low BP that one would have expected. They tended to have the highest BP &amp; body weight. This may be due to a poor diet in this group combined with low intensity of exercise. The group showing most benefit were those walking between 7500–9999 steps/day.</td>
</tr>
</tbody>
</table>
Key Question 4: How is the readiness to change best assessed in obese adults with LD?

No evidence was found to answer this question.

Key Question 5: What combinations of interventions are most effective for weight loss in adults with LD? Consider diet alone, diet plus physical activity and with/without behavioural interventions.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 5.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bradley, S. (2005) Tackling obesity in people with learning disability. Learn Disabil Pract. 8, 10-14.</td>
<td>Cohort study</td>
<td>Level 2-</td>
<td>9 people with LD.</td>
<td>Questionnaires used to gather baseline information.</td>
<td>Questionnaires impractical for this group as many needed help from carers which resulted in bias answers. Weight changed in 7 out of 9 participants. Those who increased exercise achieved most weight loss. Biggest subjective change was increased fruit &amp; veg. consumption.</td>
</tr>
<tr>
<td>Chapman, M.J., Craven, M.J. &amp; Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. J Intell Disabil. 9, 131-144.</td>
<td>Pre-/post-intervention study with a comparison group.</td>
<td>Level 2-</td>
<td>Adult learning disability. 50 in non-input group 38 in input group</td>
<td>The input group received advice from a Healthy Living Coordinator on ways of improving their diet &amp; lifestyle. The non-input group received no advice.</td>
<td>Input group showed significant weight loss over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial, although it does state that diet &amp; exercise can assist weight loss.</td>
</tr>
<tr>
<td>Hamilton, S., Hankey, C.R., Miller, S.</td>
<td>Review</td>
<td>Level 4</td>
<td>n/a</td>
<td>n/a</td>
<td>This paper is a review of existing evidence.</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Title</td>
<td>Year</td>
<td>Article Type</td>
<td>Level</td>
<td>Sample</td>
</tr>
<tr>
<td>-----------</td>
<td>-------</td>
<td>------</td>
<td>--------------</td>
<td>-------</td>
<td>--------</td>
</tr>
<tr>
<td>Boyle, S. &amp; Melville, C.A. (2007)</td>
<td>A review of weight loss interventions for adults with intellectual disabilities.</td>
<td>2007</td>
<td>Review article</td>
<td>Level 4</td>
<td>n/a</td>
</tr>
<tr>
<td>Jeffreys, K. (2000)</td>
<td>Managing and treating obesity in people with learning disability.</td>
<td>2000</td>
<td>Review article</td>
<td>Level 4</td>
<td>n/a</td>
</tr>
<tr>
<td>Marshall, D., McConkey, R. &amp; Moore, G. (2003)</td>
<td>Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities.</td>
<td>2003</td>
<td>Pilot study</td>
<td>Level 2-</td>
<td>Study 1: sample – 464 aged 10+ - individuals with LD attending special schools &amp; day centres. Study 2: sample 25 – adults in day centres.</td>
</tr>
<tr>
<td>Oathamshaw, S.C. (2007)</td>
<td>Delivering cognitive behavioural therapy in community services for people with LD: difficulties, dilemmas, confounds.</td>
<td>2007</td>
<td>Case report</td>
<td>Level 3</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Paper discusses behavioural problems, & the fact that success in reducing behavioural problems is linked to understanding of the function of the problem behaviour. A functional behaviour assessment must always be carried out.


Paper details cognitive behaviour therapy and how it can be modified for use with ID. Need to look at lots of factors such as ability, self-efficacy, motivation, not only of the client, but also family/carers.

**Key Question 6**: What is the level of knowledge and understanding of individuals delivering weight management interventions to adults with LD?

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 6.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapman, M.J., Craven, M.J. &amp; Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. <em>J Intell Disabil.</em> <strong>9</strong>, 131-144.</td>
<td>Pre-/post-intervention study with a comparison group.</td>
<td>Level 2-</td>
<td>Adult learning disability. 50 in non-input group 38 in input group</td>
<td>The input group received advice from a Healthy Living Coordinator on ways of improving their diet &amp; lifestyle. The non-input group received no advice.</td>
<td>Input group showed significant weight lose over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.</td>
</tr>
<tr>
<td>Marshall, D., McConkey, R. &amp; Moore, G. (2003) Obesity in people with</td>
<td>Observational study.</td>
<td>Level 2-</td>
<td>Study 1 : sample – 464 aged 10+ -</td>
<td>Study 1 : Health screening – 200 were</td>
<td>Weight loss was greater among those attending the group sessions compared with those seen by their</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 7.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cross sectional survey</td>
<td>Level 2-</td>
<td>63 carers selected – 61 completed study.</td>
<td>Questionnaires completed on carers’ knowledge of healthy diet, recommendations for physical activity and barriers to physical activity within the client group they work with.</td>
<td>It was found that carers generally had a low level of knowledge on recommendations for a healthy diet and physical activity, with greater importance being put on the health benefits of a healthy diet than physical activity. Study served to highlight the need for training of carers in the field of healthy diet and recommendations for physical activity and suggests that this should be incorporated into the induction course at beginning of employment.</td>
</tr>
</tbody>
</table>

**Key Question 7**: What are the outcomes (lifestyle changes, altered BMI) when obese adults with LD are treated by LD dietitians compared to generalist dietitians or dietitians who have specialised in obesity?

Reference

Key Question 8: In obese adults with LD, where other interventions have failed, what is the evidence of effectiveness of Orlistat and Sibutramine?

No evidence was found to answer this question.

Key Question 9: In obese adults with LD what is the effectiveness of bariatric surgery?

No evidence was found to answer this question.

Key Question 10: What are the health benefits of weight loss in adults with LD?

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 10.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marshall, D., McConkey, R. &amp; Moore, G. (2003) Obesity in people with</td>
<td>Observational study.</td>
<td>Level 2-</td>
<td>Study 1 : sample – 464 aged 10+ -</td>
<td>Study 1 : Health screening – 200 were referred on to their GP</td>
<td>Weight loss was greater among those attending the group sessions compared</td>
</tr>
</tbody>
</table>

Individuals with LD attending special schools & day centres. Study 2: sample 25 – adults in day centres. With various problems. Study 2: individuals were involved in group sessions where support & advice was given on healthy diet & lifestyle. With those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers & people with a LD to be actively involved in deciding on a healthy diet & becoming involved in suitable exercise regimes.

**Key Question 11**: In adults with LD who have achieved weight loss, which are the most effective support interventions in promoting weight maintenance?

No evidence was found to answer this question.

**Key Question 12**: How is obesity measured in adults with LD? (Consider height, weight, BMI, waist circumference.)

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 12.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapman, M.J., Craven, M.J. &amp; Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. <em>J Intell Disabil. J Intell Disabil Res.</em> <strong>9</strong>, 131-144.</td>
<td>Pre-/post-intervention study with a comparison group.</td>
<td>Level 2-</td>
<td>Adult learning disability. 50 in non-input group 38 in input group</td>
<td>The input group received advice from a Healthy Living Coordinator on ways of improving their diet &amp; lifestyle. The non-input group received no advice.</td>
<td>Input group showed significant weight loss over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.</td>
</tr>
<tr>
<td><strong>Levy, J.M.; Botuck, S. &amp; Rimmerman, A. (2007)</strong></td>
<td><strong>Exchanging outpatient health care utilization among adults with severe or profound intellectual disabilities living in an urban setting: A brief snapshot. J Soc Work Disabil Rehab. 6, 33-45.</strong></td>
<td><strong>Bivariate regression analysis.</strong></td>
<td><strong>Level 2-</strong></td>
<td><strong>52 adults with intellectual disabilities who live in New York City, who exclusively utilized a community based medical practice.</strong></td>
<td><strong>Age, gender, race, living situation, level of ID, autism, cerebral palsy, sensory impairment &amp; self injurious behaviour were obtained from individuals' most recent Developmental Disabilities Profile.</strong></td>
</tr>
<tr>
<td><strong>Marshall, D., McConkey, R. &amp; Moore, G. (2003)</strong></td>
<td><strong>Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. J Adv Nurs. 41, 147-153.</strong></td>
<td><strong>Observational study.</strong></td>
<td><strong>Level 2-</strong></td>
<td><strong>Study 1: sample – 464 aged 10+ - individuals with LD attending special schools &amp; day centres. Study 2: sample 25 – adults in day centres.</strong></td>
<td><strong>Study 1: Health screening – 200 were referred on to their GP with various problems. Study 2: individuals were involved in group sessions where support &amp; advice was given on healthy diet &amp; lifestyle.</strong></td>
</tr>
<tr>
<td><strong>Melville, C. A., Cooper, S. &amp; Morrison, J. (2008)</strong></td>
<td><strong>The prevalence &amp; determinants of obesity in adults with intellectual disability. JARID. 21, 425-437.</strong></td>
<td><strong>Cross sectional study.</strong></td>
<td><strong>Level 2+</strong></td>
<td><strong>Adults with learning disabilities in a defined area of Glasgow.</strong></td>
<td><strong>Data collected &amp; compared with results from the Scottish Health Survey (general population) 2003.</strong></td>
</tr>
</tbody>
</table>

Cross sectional study  Level 2-41 females & 52 males with mild to severe learning disability – relatively small sample. BMI assessed & results compared to general population figures. 41.4% of females were overweight and 36.6% obese (compared to 28.8% and 18.2% respectively from the general population). 30.8% of males were overweight & a further 30.8% obese (compared to 45.2% & 18.5% respectively for the general population). No significant difference between males & females. Levels of overweight/obesity varied across living conditions with the highest prevalence being in those living in carer assisted accommodation.

Key Question 13 : What screening tools are available for adults with LD to prevent weight gain/promote weight loss?

No evidence was found to answer this question.

Key Question 14: What is the prevalence of Binge Eating Disorder (BED) in obese adults with LD? Are standard obesity interventions adequate for those who have BED, or do they require additional/alternative support?

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 14.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hove, O. (2004) Prevalence of eating disorders in adults with mental retardation living in the community. Am J Ment Retard. 109, 501-506.</td>
<td>Non-experimental cross sectional survey.</td>
<td>Level 2-</td>
<td>311 adults with mental retardation in receipt of local services in an area of Norway.</td>
<td>Questionnaire retrospective over 3 months.</td>
<td>Eating disorders more prevalent in adults with mental retardation than general population. BED is the most common. The diagnostic criteria used was the DC-LD developed by the Royal College of Psychiatrists which has 7 classifications of eating disorders &amp; separates BED from other eating disorders.</td>
</tr>
</tbody>
</table>
**Key Question 15**: What are the outcomes (lifestyle changes, altered BMI) when the dietary treatment of obese adults with LD is carried out in individual consultations compared to group sessions with other obese adults with LD, compared to group sessions with other obese adults?

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Type</th>
<th>Evidence Level</th>
<th>Population and number</th>
<th>Intervention</th>
<th>Comments relating to key question 15.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapman, M.J., Craven, M.J. &amp; Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. <em>J Intell Disabil</em>. 9, 131-144.</td>
<td>Pre-/post-intervention study with a comparison group.</td>
<td>Level 2-</td>
<td>Adult learning disability. 50 in non-input group 38 in input group</td>
<td>The input group received advice from a Healthy Living Coordinator on ways of improving their diet &amp; lifestyle. The non-input group received no advice.</td>
<td>Input group showed significant weight loss over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.</td>
</tr>
<tr>
<td>Marshall, D., McConkey, R. &amp; Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. <em>J Adv Nurs</em>. 41, 147-153.</td>
<td>Observational study.</td>
<td>Level 2-</td>
<td>Study 1: sample – 464 aged 10+ - individuals with LD attending special schools &amp; day centres. Study 2: sample 25 – adults in day centres.</td>
<td>Study 1: Health screening – 200 were referred on to their GP with various problems. Study 2: individuals were involved in group sessions where support &amp; advice was given on healthy diet &amp; lifestyle.</td>
<td>Weight loss was greater among those attending the group sessions compared with those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers &amp; people with a LD to be actively involved in deciding on a healthy diet &amp; becoming involved in suitable exercise regimes.</td>
</tr>
<tr>
<td>Melville, C. A., Cooper, S. &amp; Morrison, J. (2008) The prevalence &amp; determinants of obesity in adults with intellectual disability. <em>JARID</em>. 21, 425-437.</td>
<td>Cross sectional study.</td>
<td>Level 2+</td>
<td>Adults with learning disabilities in a defined area of Glasgow.</td>
<td>Data collected &amp; compared with results from the Scottish Health Survey (general population) 2003.</td>
<td>Women with LD more likely to be obese than men. People with mild LD more likely to be obese than those with profound LD. Men &amp; women with Down Syndrome (DS) are significantly more likely to be overweight / obese than those with LD but no DS. Women living independently in a deprived area have increased likelihood of obesity but this is not the case for men. Incidence of overweight in LD population greater at an earlier age than for general population.</td>
</tr>
</tbody>
</table>
Key Question 16: What are the considerations for achieving weight loss/maintenance in obese adults with LD who are enterally fed or receive nutritionally complete supplements?

No evidence was found to answer this question.

Hierarchy and Quality Rating of evidence (Harbour and Miller, 2001).
1 Meta-analysis, systematic reviews, randomized controlled trials (RCTs).

2 Systematic reviews of case control or cohort studies, case control or cohort studies.

3 Non-analytical studies e.g. case reports, case series.

4 Expert opinion.

++ Most/all methodological criteria met, low risk of bias.

+ Some criteria met, high risk of bias

- Few or no criteria met, high risk of bias.
Appendix 3

List of rejected papers


Appendix 4

Core Members of a Specialist CLDT

- Clinical Psychologist
- Community Nurse
- Consultant Psychiatrist
- Dietitian
- Occupational Therapist
- Physiotherapist
- Social worker / care manager
- Speech & Language Therapist - Communication
- Speech & Language Therapist - Dysphagia
## SAMPLE LESSON PLAN

**GROUP:** HEALTHY EATING IS FUN GROUP. SESSION 2 OF 5  
**LOCATION:**  
**DATE:**  

**AIM:** Increase awareness of dental hygiene and healthy foods **SUGAR AND TEETH**

**OBJECTIVE(s):** PARTICIPANT'S TO DISCUSS ORAL HYGIENE  
TO EXPLORE SUGAR IN THE DIET AND IN RELATION TO THE 3 FOOD MODEL  
TO PARTICIPATE IN DISCUSSIONS AND EXERCISES

<table>
<thead>
<tr>
<th>TIME</th>
<th>TOPIC / PLAN OF SESSION</th>
<th>METHOD</th>
<th>RESOURCES</th>
<th>ASSESSMENT/EVIDENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.00</td>
<td>WELCOME BACK, Introduction to session</td>
<td>TUTOR LEAD</td>
<td></td>
<td>FEEDBACK</td>
</tr>
<tr>
<td>2.05– 2.20</td>
<td>DISCUSS TEA DIARIES</td>
<td>GROUP DISCUSSION</td>
<td>FLIP CART &amp; PENS (fit foods into 3 food model drawn on chart)</td>
<td>PARTICIPATION/ FEEDBACK</td>
</tr>
<tr>
<td>2.20 – 2.30</td>
<td>WHY WE NEED TO EAT RIGHT (RECAP from last week)</td>
<td>GROUP DISCUSSION</td>
<td>FLIP CHART &amp; PENS</td>
<td>PARTICIPATION Q &amp; As</td>
</tr>
<tr>
<td>2.30 – 2.50</td>
<td>LOOKING AFTER YOUR TEETH</td>
<td>DEMONSTRATION</td>
<td>TEETH MODEL &amp; BRUSH; samples</td>
<td>PARTICIPATION Q &amp; As</td>
</tr>
<tr>
<td>2.50 – 2.55</td>
<td>BREAK</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.55 – 3.15</td>
<td>SUGAR IN THE DIET</td>
<td>SUGAR GAME</td>
<td>HEALTHY DAY’S FOOD &amp; DRINK CHART v HIGH SUGAR VERSION.; Jam Jars x 2; bags of sugar/cubes; teaspoons X 2.</td>
<td>PARTICIPATION / ANSWERS</td>
</tr>
<tr>
<td>3.15 – 3.20</td>
<td>3 FOOD MODEL (time filler if required)</td>
<td>ODD ONE OUT</td>
<td></td>
<td>PARTICIPATION</td>
</tr>
<tr>
<td>3.20 – 3.25</td>
<td>HOMEWORK – BREAKFAST DIARIES</td>
<td>INDIVIDUAL</td>
<td>ODD ONE OUT SHEET</td>
<td>Q &amp; As</td>
</tr>
<tr>
<td>3.25 – 3.30</td>
<td>EVALUATION. HAND OUT CERTIFICATES. FINISH</td>
<td>SCORE CARDS</td>
<td>BREAKFAST DIARIES</td>
<td>SCORE CARDS</td>
</tr>
</tbody>
</table>
Healthy Meal Plan
What can I have for breakfast?

Unsweetened fruit juice

or

Fresh fruit

or

Tinned fruit in natural juice
What can I have for breakfast?

Cereal

or

Porridge

with

Low fat milk
What can I have for breakfast?

Bread and low fat spread

or

Toast with low fat spread

with

a little jam or marmalade
What can I have for a light meal?

- Soup with bread
  - Image of soup with bread

- Sandwich
  - Image of a sandwich

- Beans on toast
  - Image of beans on toast

Revision Date: September 2011
What can I have for a light meal?

- Jacket potato
- Bagel with low fat cheese
- Toasted sandwich
And there’s more . . .

Scrambled eggs on toast

or

Salad with warm bread

or

Tomatoes on toast
What can I have for a main meal?

- Spaghetti bolognese
- Lean meat with lots of vegetables
- Shepherds Pie
What can I have for a main meal?

Stir fry with noodles

or

Lasagne

or

Fish pie

Remember to have lots of vegetables
What can I have for a pudding?

- Low fat low sugar yogurt
- Fresh Fruit
- Sugar free mousse
What can I have for a pudding?

Fresh fruit salad

with

Sugar free jelly

or

Unsweetened milk pudding
Developed by:

The Department of Nutrition & Dietetics

Produced in partnership with:
The National Public Health Service

Images used include Photosymbols #3 and Widgit Writing with Symbols 2000.
Guidance for Dietitians for Records and Record Keeping

Published: August 2008, Review Date: August 2011