



Public Health
England

Protecting and improving the nation's health

Making reasonable adjustments to obesity and weight management services for people with learning disabilities

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

The Learning Disabilities Observatory

The PHE Learning Disabilities Observatory (PHELDO) provides high-quality data and information about the health and healthcare of people with learning disabilities. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare. PHELDO is a collaboration between PHE, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. The Observatory is operated by PHE and is also known as Improving Health and Lives (IHaL).

This is the 11th in a series of reports looking at reasonable adjustments in specific service areas (see Appendix A). The reports aim to share information, ideas and good practice in relation to the provision of reasonable adjustments.

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Easy-read summary



This report is about being too fat.

People who are a bit fat are called overweight.

People who are very fat are called obese.

Obesity is when you weigh far too much for your height.



A person who is obese has a lot of body fat and a big waist.



People who are obese have health problems like diabetes and heart disease.

People who are obese have more difficulty walking and getting around.



People with learning disabilities are more often overweight or obese than other people.



You lose weight by eating good food.

You lose weight by not eating fattening foods.

You lose weight by taking exercise.

Some people with learning disabilities need help.



There are services that help people lose weight. The law says everyone should be able to use public services. People with learning disabilities should be able to use them.



This report says how weight services can help people with learning disabilities.

Staff and families can use the ideas.



It describes some good services.

They use reasonable adjustments.

This helps people with learning disabilities lose weight.

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Introduction

This guidance is for public health staff commissioning or running weight management services and other mainstream health professionals working to support people to lose weight. It is also for family carers, social care staff and learning disabilities professionals. It advises about specific aspects of weight management for people with learning disabilities.

Being obese puts people at much greater risk of many important health problems including heart disease, high blood pressure, strokes, diabetes, several types of cancer and mobility difficulties. The proportion of people in the general population who are obese is high and rising. For these reasons, Public Health England (PHE) identified obesity as the first of its seven health priorities.¹

The two main ways to reduce weight are diet and exercise. For most people, bringing their weight down to healthy levels involves both exercising more and eating healthier amounts of healthier foods. Many people find that participation in some type of weight management programme helps them do this.

A higher proportion of people with learning disabilities are obese. For most of them, the diet and exercise requirements of losing weight are similar to the actions required of others. However, the task of helping them achieve this involves additional complexities. Under the Equalities Act 2010,² organisations serving the public have to ensure that the services they provide are as accessible to people with disabilities as to everybody else. This booklet is about the practical issues that can arise and how they have been tackled successfully in different parts of England.

This guidance focuses solely on the direct processes of managing weight through diet and exercise. Some people with learning disabilities have particular problems with weight control as a result of conditions such as Prader-Willi Syndrome or because of specific medications they take. These aspects of their problems are outside the scope of this guidance. However, whatever underlying causes people have for their weight problems, diet and exercise are almost always important elements in achieving and maintaining a healthy weight and the principles discussed here are relevant.

How we worked

We searched for policy and guidelines that relate to people with learning disabilities and obesity and weight management. A summary of this information is below. We looked at websites to find resources that might be of use to people with learning disabilities who need to lose weight, or to those supporting them. There are brief descriptions of these and information about how to obtain them in the resource tables.

We put a request out through the IHaL website and the UK Health and Learning Disability Network, a major email network for people interested in services and care for people with learning disabilities. We asked people to send us information about what they have done to improve weight management for people with learning disabilities. Examples of what has proven useful are given at the end of the report.

PHELDO has a database of examples of reasonable adjustments made by health services (www.ihal.org.uk/adjustments/).

People with learning disabilities and excess weight

Evidence and research

How many people with learning disabilities are overweight?

It has been recognised for many years that people with learning disabilities are at increased risk of being overweight or obese compared to the general population, with poorly balanced diets and very low levels of physical activity. This risk in turn increases the likelihood of a range of health and social problems. As noted in the PHE priorities document,¹ diet and physical activity are key factors that contribute to having an unhealthy weight and there are close links to broader social disadvantage (such as poverty, poor housing and social isolation), which is experienced disproportionately by people with learning disabilities.

The most recent data on prevalence of excess weight in adults (aged 18 and older) with learning disabilities is based on analysis of data from GPs across the whole of England. This showed that, in comparison to the general population, a smaller proportion of people with learning disabilities are in the milder category termed 'overweight' (30% of men and 25% of women compared to 41% of men and 31% of women without a learning disability). However, there are higher proportions in the more severe category of obese (31% of men and 45% of women compared to 24% of men and 27% of women without a learning disability).

Analysis of the data by locality will be made available later in 2016 on the IHaL website.

See box 1 below for information about assessing what is a healthy weight.

Box 1: Assessment of healthy weight

One established way of assessing whether a person is underweight, overweight or obese is through the measure of BMI, which relates weight to height. For adults, a BMI in the range 25 – 29.9 represents being overweight and 30+ is obese (for children BMI needs to be compared against a reference population of children of the same age and gender and there are special reference charts for children and young people with Down syndrome).

The British Dietetic Association cautions³ that chronic constipation is a frequent problem for people with learning disabilities and this can distort assessment of weight. In addition, BMI is not always an appropriate measure for people with atypical body shape and there can be challenges in measuring height and weight accurately for some individuals. Some reasonable adjustments to consider include:

- seated or hoist scales, or scales that will accept a wheelchair
- measuring height with a tape measure
- measuring height with a rollameter
- measuring height with the person lying down

Setting a weight loss target may be an acceptable alternative to measuring a change in BMI for adults (not for children, unless clinically advised to do so).

Other common ways of measuring fatness include measuring a fold of skin and measuring the waist. Adult waist sizes are linked to risk of health problems:⁴

- increased risk of health problems: men \geq 94cm, women \geq 80cm
- greatly increased risk of health problems: men \geq 102cm, women \geq 88cm

Impact of excess weight

For the general population,¹ being overweight is associated with increases in the risk of cardiovascular disease, diabetes, some cancers, stigma and bullying in childhood and poor mental health in adulthood. PHE estimates that 70,000 premature deaths in the UK could be avoided each year if UK diets matched nutritional guidelines.

Data on people with learning disabilities from the analysis of primary care data described above shows that people with learning disabilities have substantially higher rates of conditions associated with being overweight, such as diabetes, heart failure and strokes.

Mental ill health, bullying and abuse are all more commonly experienced by people with learning disabilities than in the general population,^{5,6} but no estimates are available to show what contribution excess weight may make to these problems of health and wellbeing.

Prevention and management of excess weight in people with learning disabilities

The British Dietetic Association consensus statement³ on weight management in adults with learning disabilities, based on a literature review and clinical experience, concluded there was little robust research on longer-term weight loss strategies for people with learning disabilities, but argued that “insufficient evidence should not be used as justification for the non-provision of services”.

Below is a brief review of some of the evidence around the issues to consider when working to support people with learning disabilities to manage their weight. There are implications for people with learning disabilities, supporters (family carers and paid staff) and health professionals (both mainstream and learning disabilities specialists).

Raising awareness of excess weight with people with learning disabilities (and family carers)

Recent (unpublished) research looked at perceptions of weight in young people with learning disabilities in comparison to young people without learning disabilities. The results suggested that people with learning disabilities were likely to hold more positive beliefs about their bodies, irrespective of their size. Women with learning disabilities tended to perceive their bodies as being smaller than they were. This finding has implications for the approaches needed when supporting people with learning disabilities to lose weight.

It has been shown that the main barrier to participation in physical activity for people with learning disabilities was the lack of understanding of its benefits.⁷ There is mixed evidence about people with learning disabilities' knowledge about healthy living.^{7,8} The British Dietetic Association consensus statement³ notes that people can be motivated to change if they are supported to understand more about the possible effects of their choices about diet and physical activity. People with learning disabilities may benefit from health promotion work to help them to understand the health risks of being overweight. This knowledge might be necessary if they are going to maintain healthy lifestyle changes.⁹

Annual health checks

Annual health checks¹⁰ are an opportunity for holistic review of a person's health, lifestyle, medication and interrelated risks to health and wellbeing. It is now a requirement that a health action plan is produced following an annual health check. Health action plans provide a structure for agreeing actions based on the results of the health check. In relation to weight management there might be actions for clinicians, the individual and their supporters. Possible examples are:

For clinicians:

- review and possibly change medication that affects weight
- alter nutrition where this is assisted by gastrostomy
- management of diabetes

For the individual:

- eating more healthily
- taking more exercise

For family carers or paid social care staff:

- helping to motivate the individual to eat more healthily and take more exercise
- helping the individual to plan and cook more healthy meals
- supporting the individual to be more active
- having a role in implementing any best interests decisions about diet and physical activity

The role of families and social care staff

Weight loss interventions are more effective if supporters (family carers and/or paid staff) are included.^{3,9,11} They can help to provide both motivational and practical support. When paid staff and family carers are involved, it is important that there is a consistent approach from everyone.^{12,13}

Research has identified inadequate support as a major barrier to healthy living.⁸

Problems include:

- supporters' lack of knowledge about buying and cooking healthy food – there is a need for training and good information for families and paid staff^{3,8}
- lack of time – this often leads to the frequent use of ready meals. Shopping for, and preparing, healthy meals can be time-consuming⁸
- the use of food and drinks as a reward or means of control³
- over-reliance on unhealthy activities, for example driving to a café or pub³
- supporters making unhealthy choices themselves – staff need to be encouraged to become healthy role models⁸
- limited staffing can make it difficult to attend exercise classes or take part in health activities⁸
- lack of understanding of the principles of choice and control (see section on pages 14-15)

Improving Health and Lives collaborated with the Voluntary Organisations Disability Group to develop a health charter for social care providers, setting out the roles of support providers in promoting health and supporting access to healthcare.¹⁴ This is accompanied by guidance for commissioners and providers.

Ensuring mainstream programmes are accessible to people with learning disabilities

People with learning disabilities may not always be able to access the plethora of weight loss programmes that are available to the general population. There is a need for adaptations to be made to these in order for them to be accessible to people with learning disabilities.¹² The evidence shows that:

- mainstream health promotional resources are likely to require literacy skills and often use abstract images⁷ – accessible information and resources are needed
- people with learning disabilities benefit from a multi-disciplinary and multi-component approach that takes an individualised approach^{9,12,15}
- people need support to understand the risks to their health to aid sustained motivation – training and appropriate information can help people to feel more positive about physical activity⁷
- the involvement of peer partners without disabilities, who provide reciprocal support, has been shown to encourage participation in exercise in community settings¹⁶

Examples of accessible weight management programmes are included in this report (see page 22).

Environmental, social and personal factors

There are a range of practical barriers to healthy living for people with learning disabilities that need to be overcome. These can have an impact on people's ability to eat healthily or to engage in regular physical activity. They include

- transport issues⁸
- financial constraints⁷
- immobility and illness¹⁷
- risk assessment issues⁷

There may also need to be wider consideration in terms of individualised planning. Decisions about where the person will live should embrace practicalities such as access to food shops, sports and leisure facilities, and opportunities to reduce reliance on cars. It is important to think about the person's options within their daily routines and what is acceptable or possible both to them and to others around them (such as other members of the household).

Capacity and choice around diet and physical activity

Issues of capacity and choice around diet and physical activity are often cited as problematic by people with learning disabilities, by families and by services. Difficulties can include:

- supporters (family and/or staff) struggling to contribute to best interests decisions
- dilemmas about balancing choice and the duty of care, and balancing different risks and benefits. Paid supporters can feel limited in their capacity to influence food choices¹³
- supporters misusing the right to make unwise decisions as an excuse for not helping the person to understand risks and options properly¹⁸

Risk assessment issues have been identified as one of the main barriers to physical exercise.⁷ The Health Equalities Framework¹⁹ offers a tool that can be used by people with learning disabilities, family carers, support workers and health practitioners to discuss risks to health and wellbeing. It encourages discussion about balancing risks: for example, the risks posed by being overweight alongside the risks of limiting choice.

Resources

The four tables that follow list all the information and resources we have found in relation to the management of excess weight.

- Table 1 lists guidance about the management of excess weight. This information is likely to be of use to commissioners, service managers and clinicians
- Table 2 lists resources for practitioners, family carers and support staff. This includes leaflets, templates, web-pages and videos. These resources are not easy-read
- Table 3 lists all the easy-read resources we have found. This is where you can find information to use with people with learning disabilities
- Table 4 shows where relevant free apps may be found (not specific to people with learning disabilities)

Some resources may be available from more than one site, but we have only given one link. We have only included resources that are free to download, although some of the websites also include resources you can buy.

Table 1: Guidance about the management of excess weight

Theme	Description	Provider	Link
PHE obesity website	Provides a single point of contact for wide-ranging, authoritative information on data, evaluation, evidence and research related to weight status and its determinants	PHE	http://www.noo.org.uk/
PHE obesity resources	Slide sets with facts and figures about child and adult obesity, including a set on why it is important for local authorities and others to invest in tackling obesity, with potential routes to action. There is an accompanying reference sheet	PHE	http://www.noo.org.uk/slide_sets
Government report on interventions to reduce sugar consumption	Report on the evidence on interventions to help the nation reduce sugar consumption	PHE	https://www.gov.uk/government/publications/sugar-reduction-from-evidence-into-action
Government guidance on catering for adults and older people	Catering guidance that offers practical advice for services (such as residential and day services) on how to make catering affordable, healthier and more sustainable. The principles and tools can also inform those supporting individuals	PHE	https://www.gov.uk/government/publications/healthier-and-more-sustainable-catering-a-toolkit-for-serving-food-to-adults
Eatwell guide	The eatwell guide is a policy tool used to define government recommendations on eating healthily and achieving a balanced diet. Using the five food groups, the guide represents visually how different foods contribute towards a healthy balanced diet	PHE	https://www.gov.uk/government/publications/the-eatwell-guide
School Food Plan standards	Standards and practical guidance, to be used alongside government buying standards for food and catering services	The School Food Plan, with the support of the Department for Education	http://www.schoolfoodplan.com/standards/
Obesity pathway and	Pathway with linked guidance, resources and standards. Covers children and adults	National Institute for Health and	http://pathways.nice.org.uk/pathways/obesity

Theme	Description	Provider	Link
guidance		Care Excellence	
Nutrition and hydration guidance for commissioners	Guidance and examples to support commissioners to improve the nutritional and hydration needs of their populations	NHS England	https://www.england.nhs.uk/commissioning/nut-hyd/

Table 2: Resources for practitioners, family carers and support staff

Theme	Description	Provider	Link
Weight management for people with learning disabilities	Consensus statement (available on request) intended to inform and support the practice of dietitians who are not undertaking a specialist learning disabilities role, but within their caseload care for adults who are overweight/obese; also a useful resource for other practitioners. Contains examples and resources as well as good practice points	British Dietetic Association	https://www.bda.uk.com/
Weight Wise website	Practical advice, tips and resources on weight management for the general public. Not specific to people with learning disabilities, but plain English	British Dietetic Association	http://www.bdaweightwise.com/
Change4Life website	Practical advice, tips, activities and resources for families and the general public. Not specific to people with learning disabilities, but colourful and plain English	NHS	www.nhs.uk/change4life
Weight loss guide	Twelve week plan combining advice on healthier eating and on physical activity. Not specific to people with learning disabilities, but fairly easy to follow	NHS Choices	http://www.nhs.uk/livewell/weight-loss-guide/Pages/weight-loss-guide.aspx
Eating well: children and adults with learning disabilities	Evidence-based report and training pack (164 pages) that summarises available information on the nutritional needs of children, young people and adults with learning disabilities. It covers food choice and eating well, and provides practical information.	Caroline Walker Trust	http://www.cwt.org.uk/publication/eating-well-supporting-adults-with-learning-disabilities-training-materials/ Go to publications list to download or order. Free to

Theme	Description	Provider	Link
			download (with request to consider donation); hard copies with CD can be purchased via Amazon
Top tips for happy mealtimes	Tips from a mother about teaching children with learning disabilities good eating skills	NHS Choices	http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/eating-tips-special-needs.aspx
Managing weight with a learning disability	Advice from a dietitian about how to think about the lifestyle of the person you care for, and how it can be changed to promote a healthy, balanced diet and to include more physical activity, if needed. Includes links to tools and videos	NHS Choices	http://www.nhs.uk/Livewell/Disability/Pages/weight-management-learning-disabilities.aspx
Losing weight for people who use wheelchairs	Advice on diet and physical activity	NHS Choices	http://www.nhs.uk/Livewell/Disability/Pages/weight-loss-wheelchairs.aspx
West Midlands good practice briefing: learning disability and obesity	Briefing on health inequalities and health equity issues related to weight management in people with learning disabilities, with examples of local best practice	PHE West Midlands	http://www.lfphwm.org.uk/library/publications/obesity/doc_download/536-west-midlands-good-practice-briefing-learning-disability-and-obesity
Prader-Willi Syndrome Association website	A range of downloadable information, including on nutrition and weight management. Some resources are also available to buy	Prader-Willi Syndrome Association	http://www.pwsa.co.uk/information-support-advice/publications/
Preventing heart disease	Heart health advice and resources for practitioners and the general public, including healthy eating and staying active. Includes advice for some specific ethnic groups, and some videos in British Sign Language. See Table 3 for resource aimed at people with learning disabilities	British Heart Foundation	https://www.bhf.org.uk/heart-health/preventing-heart-disease
The Lifestyle Elf website	Digests and updates on research, guidance and policy related to lifestyle, including healthy eating and physical activity	The Lifestyle Elf	http://www.thelifestyleelf.net/

Theme	Description	Provider	Link
One You campaign	Quiz and resources on healthy lifestyles. Not specific to people with learning disabilities, but easy to follow	PHE	https://www.nhs.uk/oneyou#hpxp7muFkwHHhkBW.97
Weighing a person who uses a wheelchair	Guide to using wheelchair scales	Hertfordshire Partnership University NHS Foundation Trust	https://www.improvinghealthandlives.org.uk/adjustments/?adjustment=389

Table 3: Easy-read resources

Theme	Description	Provider	Link
Live with a healthy heart	Booklet and DVD to help people with learning disabilities think and talk about healthy lifestyles. The DVD features people with learning disabilities talking about what they have done. The booklet includes guidance notes for supporters. The resource was evaluated positively by two groups of people with learning disabilities who had not been involved in developing it	British Heart Foundation	https://www.bhf.org.uk/publications/healthy-eating-and-drinking/live-with-a-healthy-heart
Easy health website	Range of easy-read leaflets on healthy eating, physical activity and obesity. A few videos are also available (one made with and for people with learning disabilities)	Collected from a number of sources (each credited) by the easy health team at Generate	http://www.easyhealth.org.uk/categories/food-and-exercise and http://www.easyhealth.org.uk/listing/healthy-eating-%28videos%29
A Picture of Health website	Range of easy-read leaflets on healthy eating and physical activity	Collected from a number of sources (each credited) by the team at A Picture of Health	http://www.apictureofhealth.southwest.nhs.uk/healthy-life-styles/diet/ and http://www.apictureofhealth.southwest.nhs.uk/healthy-life-styles/exercise/
Healthy eating	Easy-read resource covering food groups, portion sizes,	Plymouth City	https://www.improvinghealth

guide	checking weight and tips for losing weight	Council	andlives.org.uk/adjustments/?adjustment=391
Resources for people with Prader-Willi syndrome	Quarterly newsletter; <i>Our Way of Life</i> booklet (one copy free to people with Prader-Willi syndrome)	Prader-Willi Syndrome Association	http://www.pwsa.co.uk/information-support-advice/people-with-pws/

There are also relevant resources for professionals and people with learning disabilities listed in the earlier IHaL reasonable adjustment report on diabetes. This can be found at <http://www.improvinghealthandlives.org.uk/gsf.php5?f=16981>

Table 4: Apps related to obesity and weight management

Theme	Description	Provider	Link
Health and fitness trackers	Range of apps to support weight management (designed for general use, not adapted for people with learning disabilities)	NHS Choices	http://www.nhs.uk/conditions/nhs-health-check/pages/tools-and-technology-that-can-help.aspx
Eating well	Range of apps to support healthy eating (designed for general use, not adapted for people with learning disabilities)	Change4Life	http://www.nhs.uk/Change4Life/Pages/healthy-eating.aspx

Examples of reasonable adjustments and case studies



This symbol indicates that the case study contains an example of a weight management group programme.



This symbol indicates that the case study contains an example of one-to-one personalised working.



This symbol indicates that the case study illustrates joint working between specialist learning disability services and mainstream services.



This symbol indicates that the case study is an example of how to work with/train family carers and paid supporters.



This symbol indicates that the case study provides an example of strategic change.



This symbol indicates that the case study has included some formal evaluation.

Derbyshire's 12-month challenge



Derbyshire Healthcare NHS Foundation Trust has a long track record of initiatives to improve healthy eating and physical activity among people with learning disabilities. The lead strategic health facilitator worked with informatics and commissioning colleagues to extract data from primary care systems. This demonstrated that levels of obesity were higher among people with learning disabilities (75%) than in the general population (25%).

The data was used to convince commissioners and public health services about the need to improve access to weight management services for people with learning disabilities. The lead strategic health facilitator worked with the healthy lifestyle services in Derby and Derbyshire to increase awareness and referrals from primary care and to develop and launch a “12-month challenge” to support weight loss. This programme attracted funding from district councils. In addition, a dietitian was funded to run specialist weight management groups in two areas.

The “12-month challenge” is a workbook to help people with learning disabilities to learn and understand more about:

- healthy eating
- exercise
- and to encourage behaviour change

with a view to them losing weight, increasing their physical activity levels and becoming healthier, fitter and slimmer over a 12-month period. The tool helps health professionals to raise the issue of weight and weight loss with their patients and their supporters (family or paid workers). The workbook offers a different topic for each month, encouraging people to make small changes and to record progress. The workbook is available to download at

<http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=388>

The programme has been promoted via posters, leaflets, presentations, promotional tape measures, inclusion in training (for example, linked to diabetes), and via nursing forums and the GP portal.

A guide for provider services to deliver the 12-month challenge information to people with learning disabilities has been developed. This will be given to services who attend training with the Derbyshire Live Life Better (healthy lifestyle service) later this year (2016). The original pilot of the 12-month challenge was with a MacIntyre day service. While the primary intention of the programme was to train staff and carers to support

learners, six out of the 12 learners who attended the session lost over 5% of their body weight, with one individual losing over four stone. All the learners increased their activity levels or made healthy changes to their eating habits, such as eating more fruit and vegetables and consuming less food that was high in fat and sugar. The 12-month challenge is currently (spring 2016) being delivered with a larger Derbyshire day service involving around 50 people, with encouraging early results. Other day services are using the workbooks and will be invited to the training. The Derby Live Ability service has provided weight loss advice to over 100 people with learning disabilities and has consistently shown increased activity levels; the service continues to use the 12-month challenge model.

For further information contact Jackie Fleeman at jackie.fleeman@derbyshcft.nhs.uk

Health promotion service, Cornwall



Cornwall's health promotion service includes several different strands of work aimed at the whole population, including health trainers, groups (such as walking and swimming), and courses (including healthy weight). These all accept referrals of people with learning disabilities, including self-referrals. Easy-read materials are available and activities are tailored to the individual, with support to encourage each person to stretch themselves. The service also includes the Champs team of ambassadors for inclusion of people with learning disabilities, which offers some specific programmes and also disseminates information throughout the service about activities taking place that might be appropriate for people with learning disabilities.

One of the health trainers, Graham Hicks, describes his way of working with everyone as being based on getting to know the person and their circumstances, planning advice and support matched to their needs and preferences, and focusing on their whole lifestyle – including their confidence and commitment to change. Training people to feel more in control and boosting their confidence are integral to his approach. Up to 20% of Graham's clients have a learning disability or autism and he adjusts his practice to suit each individual: for example, using easy English, seeking suitable materials and activities, and involving any supporter (such as a family member or support worker) so that they understand the goals and can support and encourage the person.

One person that Graham supported, Ann Marie, needed help to eat more healthily and incorporate some regular exercise into her life. Graham worked with her one-to-one, involving supporters at her work placement, and helped her discover and nurture her own willpower. She also attended the 12-week healthy weight course. Graham

contributed to discussions about a possible move for Ann Marie, thinking for example about access to shops that could offer healthy food choices. The weight loss Ann Marie achieved improved her health and she felt happier as a result; Graham presented her with a certificate of achievement to encourage her to keep going.

For further information contact Graham Hicks at graham.hicks@nhs.net

Another health trainer, Helen Page, supports the “Eat Well Spend Less” community cooking group that meets weekly in Redruth to prepare, cook and eat a two-course meal. The group is friendly and inclusive; it usually includes ten people with learning disabilities.

The aim is to encourage people to eat a balanced, healthy diet that is affordable. The group was developed from the Eat Well Spend Less cookbook (<https://www.healthpromcornwall.org/projects/health-trainer-service/eat-well-spend-less-book-/>) as the health trainers recognised that not everyone has the skills or confidence to cook. An A4 easy-read format of the cookbook with a DVD was produced. The group also uses an easy-read health and safety checklist at the beginning of each session to remind participants about washing their hands and other important routines.

As well as cooking skills, people benefit from sharing a meal with others, which helps with improving their social skills and wellbeing and reducing isolation. The group has had Christmas parties, pancakes on Shrove Tuesday, interactive sessions about healthy eating, a slow cooker workshop (with a free slow cooker from Community Energy Plus) and lots of opportunities to try new foods.

For further information contact Helen Page at helen.page11@nhs.net

Halton Health Improvement Team



Discussion with Halton’s adult learning disability team showed that local obesity levels were similar to those identified in research studies and that there were gaps in provision of weight management support. Learning disability nurses reported that people attending community services struggled to understand health messages and information or did not even attend interventions. The health improvement team and the adult learning disability team set about designing a bespoke weight management programme for people with learning disabilities to provide both clients and care workers with the education and support to enable them to make informed lifestyle choices. They researched best practice and current resources (from NHS services and Easy Health)

and undertook training on how to adapt resources to be more accessible and user-friendly.

The draft content of the programme was tested with groups of people with learning disabilities to produce a truly tailored package. For example, the programme is mainly delivered through practical elements, any written resources use more pictures than text, and the exercise component is based around games rather than traditional formal exercise sessions.

The programme provides weekly group education around healthy eating, portion sizes, fats, sugars, takeaways and physical activity. Participants can be weighed, observe a food demonstration and taster, and take part in 30 minutes of physical activity. Care workers are encouraged to attend to support their clients and to take part, as there is strong evidence that combined group sessions are effective and weight loss interventions need to include support and motivation to be successful.

Since the pilot programme started in December 2013, over 60 people with learning disabilities have attended the bespoke “Fresh start” weight management programme. Over 80% completed the course; over 90% showed improved knowledge about healthy eating and physical activity as a result of the course. In addition, 70% of clients achieved weight loss, with one client losing 7.1kg. Participants have given some glowing feedback and testimonials.

While respecting individuals’ rights to choose, it is essential that a person with learning disability be given appropriate information about healthy food and the benefits so that they can make informed decisions. In addition to involving care workers in the weight management programme, a full-day training session was designed on the principles of healthy eating and physical activity recommendations to ensure that care staff felt they had the knowledge and confidence to support their clients. To date 28 care workers have been trained, with all reporting excellent knowledge and confidence outcomes enabling a greater level of support and understanding for clients attending the sessions.

The next phase of the programme involved the health improvement team training peer advocates, care workers and other staff to level 2 in “Understanding health improvement” (a Royal Society of Public Health qualification), to assemble a robust group of networking mentors with the aim of sustaining the programme. This pool of trained people will run “Refresh” support sessions that meet weekly or monthly to discuss various health topics and offer internal support, motivation, and ideas to maintain healthy lifestyles. People with learning disabilities who have completed the bespoke “Fresh start” programme will also be able to attend any of the mainstream “Next steps” courses for physical activity and weigh-in. A local network group has evolved that meets regularly, putting on exercise interventions and education sessions to ensure sustainability.

For further information contact David King or Cheryl Rose-Coulthard at david.king@halton.gov.uk or cheryl.rose-coulthard@halton.gov.uk

Bristol Meals Service: support at work to manage weight



Chris works as an operations assistant at the Bristol Meals Service. A job coach supported him to apply for the job and then worked with him to help him settle in, learn the job and find the best route to work. They helped Chris with his benefits and application for working tax credits. He had never had full-time work before and found it very tiring at first, so they also helped him get advice about changing his diet and a routine for getting a good night's sleep.

One of the perks of the job was that staff could eat any meals left at the end of the day. However, this presented difficulties for Chris. How many could he eat? Was it all right to eat two or three, with pudding, as well as the packed meal he brought in from home? He gained weight and before long his clothes no longer fitted him.

Chris was supported to discuss his weight and he agreed that it would be better not to eat the leftover meals except on special occasions. Job coaching support helped Chris to work with his manager, a nutritionist, who helped him design and implement a weight-reducing diet that would be easy for Chris to understand. She offered to check Chris's packed lunches and undertook to ensure he understood the types of foods he should be buying. Chris was very proud that he lost weight and would often explain his healthy packed lunches to other staff.

Although Chris had regular staff induction and supervision, it became evident that he would benefit from ongoing support to enable him to stay in work. Consideration and support given by his managers and colleagues around his health and lifestyle allowed Chris to become a successful member of the team.

For further information contact Keith Bates at keith@mutuallyinclusive.co.uk

Merton community learning disability team



The community learning disability team in Merton includes a physiotherapist, Charis Hollies, whose role includes working with some individuals on weight management, healthy eating, activity and lifestyles. She works closely with a psychologist in the team on motivation, with other team colleagues and with a dietitian in the mainstream service.

She encourages her clients to use a range of local resources, such as gyms, swimming pools and cycling groups; the local YMCA also offers classes for people who need a bit of extra time or support in order to participate. Using a room in a local day service, Charis offers some one-to-one sessions for people who are too anxious to take part in a group or who cannot attend for some other reason.

Charis worked with Isaac and his mother to review his diet and levels of physical activity, as he had gained a lot of weight (some of which could be due to his medication). Charis found that his diet was quite good, but that he needed to take more exercise. Walking instead of taking the bus was one way of building more activity into his life. Isaac's mother also got him to try an exercise bike at the gym and then got one for him at home. She devised healthier treats for Isaac to enjoy when other people were eating crisps and chocolate. Charis offered one-to-one sessions, with support from Isaac's mother, in view of his anxiety, and put together a variety of enjoyable activities and games. Isaac loved the trampoline, boxing a pillow and games that involved running about with music playing. After about a year he had lost 1.5 stone, though he tended to gain weight during short breaks away from his mother.

Working with a person's family was vital in the case of another man who had become very obese. Charis worked with the psychologist and nurse from the team, together with the dietitian, the family GP and the man's college tutor to find out what he enjoyed (other than watching television and eating) and what could motivate him to try new foods and activities. The team made easy-read advice and also provided this in the family's first language, so that everyone could help with reinforcement. The nurse helped the whole family to make some simple dietary changes, such as buying semi-skimmed milk, and Charis helped the college to involve the man in walking and dancing. She also encouraged the man's brother to play football with him and to join in with games that Charis devised. The man has now lost some weight and understands that his father's heart attack was, as he said, "a wake-up call".

For further information contact Charis Hollies at charis.hollies@merton.gov.uk

Devon: working with people with learning disabilities around weight



Phill Howe and Linda Hancox are primary care liaison nurses/community learning disability nurses who have worked with dietitians and health trainers in Devon to improve weight loss advice and support to people with learning disabilities. They provided "top tips" for health trainers with straightforward suggestions for reasonable adjustments, such as simplifying language, providing very concrete instructions,

checking understanding and trying one new idea at a time. These tips were supplemented with easy-read examples of recipes and menu planners, with suggestions for simple swaps to encourage healthier choices. A presentation about their work, including the top tips, can be found along with some examples of the resources they have developed at

www.improvinghealthandlives.org.uk/adjustments/?adjustment=393

Linda and Phill devised an adapted programme, “Weightwise”, that can be delivered to individuals or groups. Based on collaboration with dietitians, it offers a simple way of calculating an individual’s energy requirements and the changes needed for the person to lose weight. This is followed by advice on introducing small changes to diet and lifestyle, with regular monitoring to support motivation.

A vital complement to work with the individual is work with supporters (family and/or support workers) to ensure that they understand the aims for the individual, are familiar with the tools and techniques, and will provide consistent support both during and after interventions from Phill and Linda. For example, a separate course was delivered to the support team for a group of people living in a block of flats. This enabled staff to understand elements of the programme such as:

- the five a day competition
- the taste test (comparing high fat or sugar products with healthier versions)
- the eatwell plate
- making sense of packaging

Achieving sustained support for change can be difficult, especially when support hours are very limited or when supporters are not well informed or motivated about healthy lifestyles themselves. Sometimes, very simple suggestions can help even in these circumstances, however. For example, one woman used to go shopping in the supermarket with her supporter and would become very agitated if the supporter tried to divert her from choosing her favourite doughnuts. Changing to online shopping made it possible for the woman to choose from lists that the supporter set up, away from the temptation of the sights and smells in the shop.

Linda and Phill reviewed the whole pathway of obesity services across Devon and offered advice on improving inclusion. They also noted a need for accessible exercise classes and used an award from the Queen’s Nursing Institute to develop a bespoke programme. “Fit for life” offers a weekly class run by a personal trainer who has worked with people with learning disabilities before; the classes are supplemented by an exercise DVD that participants can take home and a healthy eating calendar. The programme is now self-funding: participants pay a very small weekly fee.

Phill and Linda are willing to share further resources such as simple, healthy recipes and meal planning guides. For further information contact Phill Howe or Linda Hancox at philliphowe@nhs.net or linda.hancox@nhs.net

Dudley: strategy to action



Dudley’s joint health and social care learning disability commissioning strategy and market position statement for 2014–2016 includes a section on obesity and creates robust links with the Dudley Council plan for healthy lifestyles and with the healthy weight strategy and improvement plan. Some of the actions that follow are for everyone (for example, attention to the environment and travel options), some represent reasonable adjustments to include people with learning disabilities in universal programmes (such as healthy school food, “making every contact count” and a range of weight management programmes), and there are some pathways and programmes that specifically target children and adults with learning disabilities. The latter include a 15-week programme combining healthy eating and physical activity, a walking group and training for carers.

For further information see <http://www.dudleyld.org/weight-management-services/>

Happy, healthy and well: weight management programme in Kensington and Chelsea



A physiotherapist and a therapy assistant from the community learning disability team in Kensington and Chelsea collaborated with a specialist dietitian in 2014 to pilot sessions of the “Happy, healthy and well” weight management programme designed for adults with learning disabilities. Following the success of this programme, a further one was delivered in 2015.

The programme included weekly sessions of 90 minutes for six weeks. A typical session incorporated: healthy lifestyle advice, an educational dietary session around healthy eating and weight management, and aerobic and dance exercise. The penultimate session involved either walking to the park or a healthy shopping visit to the supermarket. Appropriate resources such as food models and pictorial aid booklets (for

Making reasonable adjustments to obesity and weight management services for people with learning disabilities

example the healthy eating and gentle exercise booklet available to buy from NDR-UK) were used to support key dietary messages.

Each programme was attended by a group of ten adults with learning disabilities (men and women) and their support workers, although attendance dropped during the course for various reasons. Support workers were required to participate fully in the sessions to make them all-inclusive and interactive.

An additional two review sessions were held at approximately monthly intervals to recap on the programme and to check the progress from the outcomes recorded in the final sessions.

At the start of each programme participants had their weight, height and BMI measured, their blood pressure taken and their personal diet baselines discussed. In the final sessions, weight, BMI and blood pressure were measured for comparison. Two people lost weight, three maintained their baseline weights and one gained weight. Other benefits included:

- increased confidence, leading to positive changes in behaviour (for example, increased interactions with others, tolerance of exercise and readiness to accept challenges)
- improved self-esteem through dancing and the possibility of gaining experience as a voluntary aerobic dance session leader
- support workers feeling more empowered to facilitate healthier food choices

For further information contact Vladimir Rokvic or Sangeeta Seedher at vladimir.rokvic@rbkc.gov.uk or sangeeta.seedher@clch.nhs.uk

WILD: weight loss study at the University of Sheffield for people with learning disabilities



Research at the University of Sheffield (spring 2016) is studying the feasibility of making reasonable adjustments to a mainstream slimming programme (<http://wild.group.shef.ac.uk/>). Funded by the Medical Research Council, the researchers chose to work with Slimming World because of its multi-component intervention, its emphasis on non-judgemental peer support and its openness to inclusive approaches.

People with learning disabilities are on the steering group for the study and existing groups contributed at the start to discussions about experiences of joining groups and

different ways of getting information about health topics. The researchers conducted a survey to find, and then interview, people with learning disabilities who had already taken part in Slimming World groups and consultants (group leaders) who had experience of including people with learning disabilities. A variety of adjustments were suggested by different people: for example, some found the social aspects of being part of a group the most challenging, whereas others wanted more support with understanding and sticking to a plan.

Learning from these discussions and interviews informed suggestions to Slimming World about adaptations that could be made: simplifying information, producing easy-read materials and developing complementary information for family carers and support workers (emphasising the importance of their involvement). Slimming World developed some prototype materials that were tested in a feasibility study. Ten people joined different groups; two dropped out after a week and eight completed the eight-week programme. It is clear that the role of supporters was very important both to participation in the groups and to behaviour change between group sessions. Other early findings include challenges around informed choice, the skills of supporters and difficulties posed by menu planning for those living in a communal setting. The eight people who completed the programme each had a supporter and all lost weight. The full results are being analysed and publication is expected by autumn 2016.

For further information contact Liz Croot at l.croot@sheffield.ac.uk

Watching our weight, Lancashire



Watching our weight (Wow) was a club-based programme led by an active living co-ordinator and run twice by the Lancaster learning disability health team, with support from social care. The programme ran over 12 months, with group sessions fortnightly for the first six months and then monthly. Participants attended with supporters. The groups were planned to be fun and supportive, with an emphasis on sociability as well as learning. Members completed 'all about me' information at the start and were supported to complete food and physical activity diaries, including video, during the programme. Sessions included cooking, tastings and discussion about different foods, meal and snack options, eating out and portion sizes. Regular weigh-ins were incorporated as well as other measures such as hip/waist ratios. NHS innovation funding was used to buy equipment (video cameras, scales) and resources such as folders and monogrammed hats and aprons.

The second programme was evaluated with support from Lancaster University. Attendance levels were high and most of the 12 participants lost weight (5.9kg on average); qualitative evaluation showed that members were able to reflect on changes they had made to their eating and physical activity habits and they also reported increased self-confidence and improved self-image. Supporters also reported learning about healthy lifestyles and noted changed perceptions about the active roles participants could play in health-related choices. Both peer support and the roles of support workers were very important in enabling members to take part and to act on what they learned.

The team are in the process of establishing a new Wow programme. The challenge now is to find a way of running the programme on a sustainable basis, beyond project funding. This could include, for example, supporting delivery by a community provider through a combination of GP prescribing, individual subscriptions, personal budgets/personal health budgets and collaboration with the learning disability health team.

The outline of the programme and the evaluation of the programme can be found at www.improvinghealthandlives.org.uk/adjustments/?adjustment=394

Further detail about this programme can be found in Bartley (2001).²⁰

For further information contact Amanda Topps at amanda.topps@lancashire.gov.uk

Tees, Esk and Wear Valleys: weight loss management programme



The lifestyle, energy, activity and nutrition (Lean) programme was piloted by the Tees, Esk and Wear Valleys NHS Foundation Trust and rolled out from 2010 to 2012.

Nutrition advice and support to change behaviour were the core of the programme; participants were expected to be motivated to change and to have support from family carers or support workers. Evaluation included the views of participants. Funding was secured from commissioners for three dietetic assistants to run the programme in a variety of community venues across Redcar and Cleveland, Middlesbrough and Stockton. The ten-week programme consisted of:

- ten weekly sessions each of 60 minutes interactive education and 30 minutes physical activity
- exploration of different nutritional topics each week (for example, portion size, food labelling), using different interactive activities such as tastings
- goal setting for participants to set themselves a target for weight loss each week
- weekly weight monitoring

- weekly evaluation by participants
- a knowledge quiz at the end and award of certificates on completion

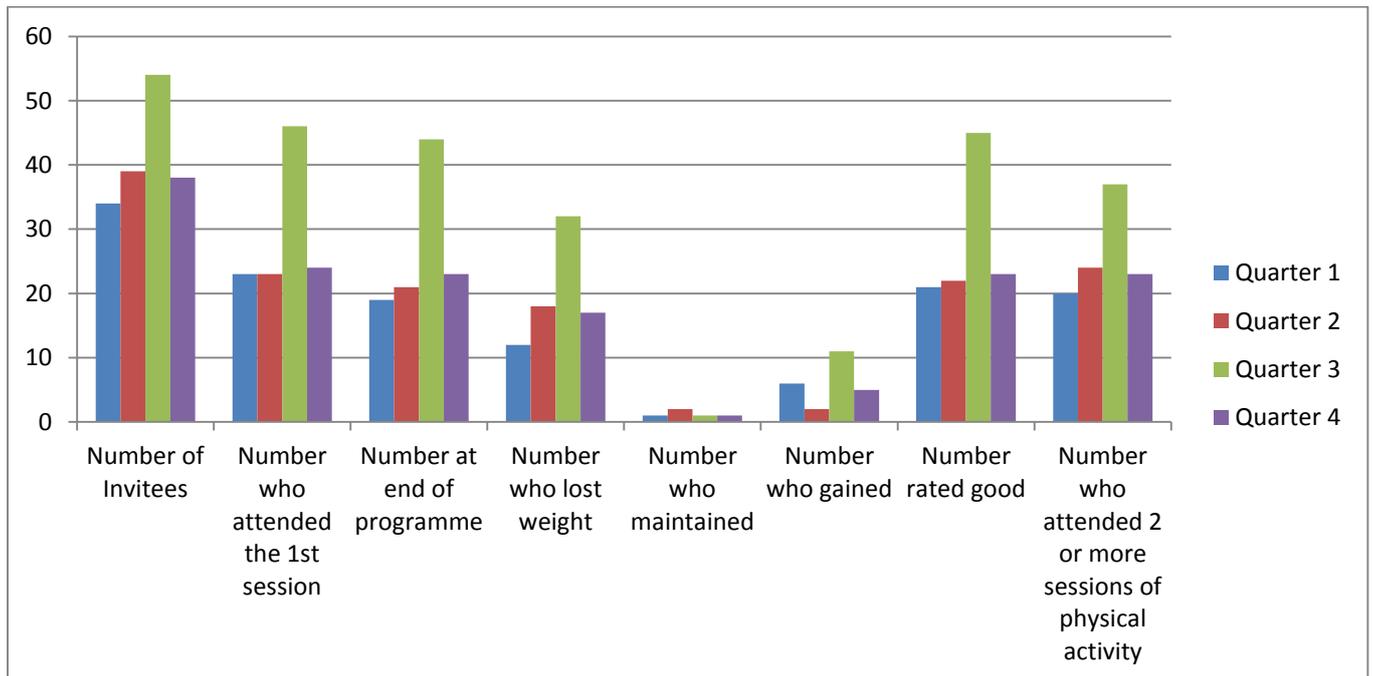
Activity sessions were planned once groups had started; this meant they could be based on participants’ ability levels and that group members could be involved in the decisions about types of activities. Exercise included indoor games (for example, hula hoop, ball games and circuit work) and outdoor activities such as walking and football. Intensity and duration were increased over time based on participants’ feedback and fitness levels, using mini goals. Most groups included one or two people who did not want to join in initially but did eventually do so; adapting the programme to the group members ensured that everyone could take part.

Challenges included organising attendance, securing sufficient support and trying to prevent supporters from undermining the learning (for example by handing out chocolate after a session).

A presentation about the programme can be downloaded at www.improvinghealthandlives.org.uk/adjustments/?adjustment=392

The collated results from the programmes are shown in Figure 2.

Figure 2. Results from Lean programmes



Source: Tees, Esk and Wear Valleys NHS Foundation Trust

For more information contact Jo Smith at jo.smith13@nhs.net

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All web links checked August 2016

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Appendix A: Reasonable adjustments reports from IHaL

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www.improvinghealthandlives.org.uk/gsf.php5?f=314186

Making reasonable adjustments to cancer screening. November 2015. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=313998

Making reasonable adjustments to epilepsy services for people with learning disabilities. November 2014. Learning Disabilities Public Health Observatory.

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Making reasonable adjustments to end of life care for people with learning disabilities. July 2014. Learning Disabilities Public Health Observatory.

www.improvinghealthandlives.org.uk/gsf.php5?f=312967

Making reasonable adjustments to primary care services – supporting the implementation of annual health checks for people with learning disabilities. April 2014. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=312703

Making Reasonable Adjustments to Dementia Services for People with Learning Disabilities. September 2013. Learning Disabilities Public Health Observatory.

www.improvinghealthandlives.org.uk/gsf.php5?f=17985

Making Reasonable Adjustments to Diabetes services for People with Learning Disabilities. March 2013. Learning Disabilities Public Health Observatory.

www.improvinghealthandlives.org.uk/gsf.php5?f=16981

Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities. January 2013. Learning Disabilities Public Health Observatory.

www.improvinghealthandlives.org.uk/gsf.php5?f=16591

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