



Eating Well for Adults with a Learning Disability – a dietitian-led training course for support workers in addressing the nutritional needs of the people they support

Description

A two day training course was delivered to 93 support workers in Gloucestershire who work with adults with learning disabilities, either in supported living or residential care. Course content and accompanying materials were based on the evidence-based materials produced by the Caroline Walker Trust (7) alongside behavioural management guidance provided by the British Dietetic Association (6) and recommended in NICE guidance (5). After completing the project attendees were able to implement new nutritional approaches in their places of work which led to improved physical and mental health for the people they care for. The course was delivered as a pilot in 2011 and has now been funded by Gloucestershire County Councils 'Building Healthier Lives' Project to provide training to another 240 support workers in 2018/2019.

Context

NHS England have published their guidance (4) highlighting the importance of developing strategies to improve the delivery and commissioning of excellent nutrition and hydration care in both acute and community settings. Commissioners are asked to ensure that the health and social care organisations for which they are responsible prevent malnutrition from occurring; educate all staff, voluntary workers, patients and carers on the importance of good nutrition and hydration in maintaining better health and wellbeing, improving recovery from illness or injury and in the management of long term conditions; take into account the duties placed on them under the Equality Act 2010 and with regard to reducing health inequalities, duties under the Health and Social Care Act 2012.

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable. People with LD are more likely to be overweight and underweight than the general population. An estimated 15% of adults known to specialist LD services require some form of mealtime support (11). This may be in relation to difficulties getting food into the body, risky eating and drinking behaviours, food refusal, and often a complex interplay of factors such as sensory issues, poor dentition, visual impairment, swallowing problems, cognitive impairment and challenging behaviours. Those requiring mealtime support due to an eating, drinking or swallowing problem were found to have twice the mortality rate than expected in the general population of adults with a LD.

The National Health Service (NHS) was estimated to spend £2.3 billion in 2007 on costs directly related to obesity. The National Institute for Health and Clinical Excellence (NICE) Obesity guidelines

recognise that the prevalence of obesity is higher in those with a learning disability and that there are difficulties of access to information and support (5).

Several factors are thought to contribute to the increased risk of overweight and obesity in people with learning disabilities, including physical inactivity and low adherence to healthy diets. The consequences of obesity are particularly relevant to people with learning disabilities, who are already confronted by health and social inequalities (5).

Obesity can exacerbate disabling conditions and has been shown to contribute to the already reduced life expectancy of people with learning disabilities (5). There is currently a lack of weight management services in Gloucestershire tailored to the needs of learning disabilities service users (10). NICE Guidance emphasises that in order to provide healthcare for all and ensure equality of treatment for people with learning disabilities, services must be developed specifically with this population in mind, taking into account differences in health needs, communication problems and understanding (5).

Having a learning disability has been shown to be significantly associated with reduced referrals to external dietetic services and exercise on prescription programmes in primary care (2). Weight Management Interventions for LD which have been shown to be effective have involved multiple one-to-one sessions being delivered at the service users own home which has a large cost implication (3) and is not provided by current tier 2 obesity services in Gloucestershire. For those service users who are able to access groups such as slimming world, the support of well-informed carers with the potential to play an active role in social support, encouragement and role modelling during their weight management efforts has the potential to improve the efficacy of currently available interventions (3).

In addition to addressing obesity, the training programme also addresses the identification and early prevention of malnutrition. Malnutrition is estimated to cost the UK health economy more than £19 billion per annum (8). Improving the identification and treatment of malnutrition is estimated to have the third highest potential to deliver cost savings to the NHS (9)

Supporting someone with a learning disability to eat well can be challenging and the fact that nutritional knowledge of learning disability support workers in the community setting has been found to be poor (1) is of serious concern.

The aims of this training were to improve the knowledge and confidence of support workers in Gloucestershire to better support their service users in meeting their nutritional needs. This would then improve the health and wellbeing of the service users in their care and act as a preventative strategy for development of conditions such as constipation, obesity and type 2 diabetes, reduce incidence of choking episodes and aspiration pneumonia, reduce referrals for PEG feeding etc.

The outcomes of the training were to enable carers:

- To be able to recognise and address common nutritional difficulties associated with a learning difficulty
- To improve knowledge in identifying and preventing Overweight and Underweight in people they are working with and know the consequences of these on health
- To recognise a healthy approach to weight loss and where to go for support
- To support those who may be resistant to change

- To effectively monitor weight and dietary intake
- To provide basic nutrition support for those who are malnourished
- To recognise signs of a swallowing difficulty and what to do
- To understand the principles of a healthy diet
- To discuss healthy eating with people they are supporting
- To feel confident in planning a nutritionally balanced and palatable menu
- To be able to adapt a menu to support people with additional/alternative needs
- To know the value in involving those they are working with in their own dietary choices
- To consider developing their own food policy

Method

The training was developed and delivered by 2gether Trust Specialist Dietitian Carly Atkinson, with support in delivering the training provided by a Speech & Language Therapist, LD Nurse Specialist and student dietitians when available. Support with administration, promotion and communication was provided by the 2gether Trust Health Facilitation Team. Each training session was delivered over 2 consecutive days in a central Gloucestershire venue, free of charge to attendees, with a maximum of 30 attendees booked on each course. 4 courses were delivered in total as part of the pilot project.

Course content and accompanying materials were based on the 'Eating Well: Supporting adults with learning disabilities' Training materials (2007) written by Dr Helen Crawley and produced by the Caroline Walker Trust. The Caroline Walker Trust produce evidence based reports which provide nutritional and practical guidelines to encourage eating well among specific vulnerable population groups. These reports are put together with a multi-disciplinary working group and make a number of recommendations with the aim of improving public health and reducing health inequalities. These materials were merged with local resources and signposting information and inclusion of practical workshops to enable sharing of good practice and ideas between peers.

Attendees were asked to complete a standard Trust Training evaluation form on completion of the 2 days training.

Support with evaluating training outcomes and the implementation of practical changes was available in the form of a Gloucestershire County Council project which we were able to link in with. This enabled in-house follow up coaching sessions to be provided for those care providers who opted in (12 out of around 30 providers). These coaching sessions were delivered by a Nutritional Therapist with prior experience working in LD settings. 4-12 weeks following the training she would visit the attendees at their place of work to look at any changes implemented and any barriers which had made embedding new practice difficult. Visits to 12 different provider settings were carried out lasting 30 minutes to 2 hours. These sessions were flexible to meet the needs of the setting, and could be delivered on a one-to-one basis or with other team members and/or service users dependent on the particular barriers or queries identified. During these 12 sessions qualitative feedback was collected on any changes to service user health or wellbeing that attendees had observed in the people they support following their attendance at the Course and changes they had trialled as a result. Feedback revealed improved confidence amongst carers and implementation of a variety of changes to previous practice.

Outcomes

Qualitative feedback was collected from 89 out of the 93 people who attended the course, at the end of the 2 day's training.

When asked whether the course met the objectives outlined, 98% indicated that this was good or excellent.

When asked whether, as a result of the training, they now felt better equipped to do their job, 85% were positive that it had.

Comments received included:

'I think it is truly useful in informing support staff about nutrition (not just weight loss) and benefits of all food'

'I feel more motivated and fresh ideas for workplace'

'It has given me a lot of new things to think about and put into practice and continue'

'It will enable a food policy to be created that ensures that all service users needs are met'

'Brilliant course – a lot of interesting and important information received which I believe will help me support individuals better. The recipe book is brilliant to add variety to meals however still nutritious and flexible with individuals. Brilliant tools and gave different ways to look at things that I wouldn't have thought of myself. Trainer knowledge was excellent, information received was easy to understand and interesting'

'I have definitely learnt things I was unaware of and a few things I thought I knew have been cleared up and I am now more informed'

Staff passed this positive feedback on to colleagues and managers and a significant waiting list remained in place following completion of the training sessions.

Qualitative information was also received from attendees during follow up coaching sessions. Despite only collecting feedback from 12 different settings this provided some useful insight into any real benefits to service users following implementation of the learning that carers had received.

In terms of physical health these included:

- Significantly reduced or cessation of medication to regulate bowel movement e.g. Movicol
- Less bloating
- More energy
- Weight loss
- Clearer skin
- Improved bladder function
- Better digestion and bowel movements
- No need for PRN Movicol
- Service user with higher energy needs having snacks with better nutritional content

- Service user with specific needs getting the right nutrition (Service user had reduced kidney function and diabetes)

Additional benefits to service users noted included:

- Positive change to routine e.g. no longer sleeping in the day
- Service users enjoy meals more
- Less anxiousness about food and mealtimes
- Less challenging behaviour around food choices/mealtimes
- Service users have more control over meals and menus
- Service users more willing to try new foods
- Greater variety of foods eaten
- Change to food habits e.g. service user who 'will only eat sandwiches' – now eating hot meals
- More Service user engagement in mealtimes and food choices
- Excitement about food and meals
- More alert, calmer (Service users with PMLD)
- Service user not 'too full'
- Service user more aware of need to improve diet and how to do so in manageable ways

Even in the few weeks between first and follow up visits, staff reported positive changes to both health and behaviour. Service users themselves reported that they felt much better, having more energy and particularly less bloating and digestive troubles. As an additional bonus, several staff said that they had taken home the changes that they were making at work and had changed their and their family's meals, with positive outcomes. Carers reported that they themselves had more energy and felt better. In fact these carers were amongst the most enthusiastic about making changes to menu's having had first-hand experience of the benefits to health and wellbeing.

In addition to those short-term benefits already seen in the evaluation, it is hypothesised that the training will also see the following outcomes in the longer term:

- Improved weight management and reduced incidence and/or severity of obesity may reduce the risk of cardiovascular disease and type 2 diabetes and improve mobility.
- Better management of dysphagia may reduce the incidence of choking, aspiration and resultant respiratory tract infections
- Improvements for service users in general self-management abilities, quality of life and self-esteem.
- Carers may also benefit through increased knowledge of healthy behaviours, which could influence their own health behaviours and in turn impact the day-to-day care they provide, for example through changing shopping habits.

- The proactive, problem-solving approach used may also be empowering within the user-carer relationship
- Costs to the NHS may be reduced through decreases in use of services and medications (e.g. GP visits, due to improved health of both learning disabilities service users and their carers).

A full value ROI evaluation has not been undertaken but the cost per attendee to deliver the training is around £88 for the 2 day session plus coaching follow up. Each Carer will be working with 4-12 service users in the immediate future, and many more in their caring career. The learning from this training therefore has the potential to make a significant difference to the diets and therefore health and wellbeing outcomes of 400-1500 people with a learning disability living in Gloucestershire in the next 5-10 years.

Further research to evaluate the longer term outcomes of the project is needed to explore whether the expected health and social benefits are achieved.

Following this pilot study a further 8 sessions (to enable training of a further 240 support workers) were commissioned and delivered over the 2018/2019 financial year. We are awaiting the results of this to enable further learning.

Learning Points

People with learning difficulties are especially vulnerable to nutritional problems, some of which are complex. Many cannot access or benefit from current mainstream services. They are also vulnerable to incorrect or unhelpful dietary messages from the media, advertising, uninformed carers or peers.

The nutritional knowledge of learning disability support workers in the community setting is poor. Robust, evidence-based training is not routinely offered by most providers in Gloucestershire to their staff. Support workers have demonstrated that they are keen to improve their level of nutrition knowledge and that they find the Eating Well Programme helpful in achieving this.

It is suggested that this type of training, which addresses all of the common nutritional difficulties that service users are likely to face, alongside practical tools and resources to support behaviour change and meal planning, should be a routine part of Carers professional training to enable them to successfully support the health needs of the people for whom they care.

With a few adjustments around information on local services and pathways, this training could be delivered by Learning Disability Dietitians in other areas of the country, with an expectation that the same outcomes could be achieved.

Food is a fundamental aspect of people's lives and access to evidence-based nutritional advice and timely interventions has the potential to greatly improve health outcomes and quality of life.

References

- 1) Smith, A. & White, H. (2011) Assessment of nutritional knowledge of learning disability support workers. *J Hum Nutr Diet*, 24, 305
- 2) Smallman, S., Engel, B. & Nelson, J. (2011) Obesity services for adults with learning disabilities. *J. Hum. Nutr. Diet.* 24, 304–305.
- 3) Spanos D., Hankey C., Boyle S. & Melville C. (2014) Comparing the effectiveness of a multicomponent weight loss intervention in adults with and without intellectual disabilities. *J Hum Nutr Diet.* 27, 22–29

- 4) Guidance – Commissioning Excellent Nutrition and Hydration 2015-2018 (NHS England)
- 5) National Institute for Health and Clinical Excellence (NICE)(2006) Obesity: The Prevention, Identification, Assessment and Management of Overweight and Obesity in Adults and Children. London: NICE.
- 6) British Dietetic Association. (2011) Weight Management for Adults with a Learning Disability Living in the Community. Birmingham: British Dietetic Association.
- 7) Crawley, H. (2009) Eating Well: Supporting adults with learning disabilities, Training materials for people working with adults with learning disabilities. London: The Caroline Walker Trust
- 8) BAPEN. (2015) Nutritional Care Tool www.bapen.org.uk/news-and-media/news/bapen-nutritional-care-tool
- 9) NICE. (2011) Nutrition Support in Adults (32) Cost Saving Guidance
- 10) Ball S.L. et al (2012) The extent and nature of need for mealtime support among adults with intellectual disabilities. *Journal of Intellectual Disability Research* 56:4, 382-401