Dietary Approaches for Metabolic Syndrome, Obesity and improved Nutrition. 
The DAMSON project. 

Lay Report

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Headlines.

- A sustainable, freely available, easy to follow cookbook was produced. This included healthy recipes that individuals with learning disabilities can use. Available at [https://canvas.kingston.ac.uk/courses/12067](https://canvas.kingston.ac.uk/courses/12067).

- The project team had great pleasure of working with individuals with learning disabilities, who acted as chefs for the day. Individuals with learning disabilities contributed suggestions about which meals should be included in the cookbook. They designed meals, supported making the videos, and presented the cookbook to staff. The anonymity of the chefs with learning disabilities was maintained by avoiding filming their faces and only using close ups of their hands.

- Resources were procured which resulted in the creation of an easy to use timer (using colours not numbers for those who found counting and understanding of numbers difficult). Delegates attending the training reported that the timers could support them with other activities, where they had difficulty with explaining timings.

- Workshops included delegates from a wide range of professions and non-professional staff. Professionals included physiotherapists, dieticians, community learning disability nurses, staff working for the Clinical Commissioning Group, psychiatrists, teachers, health facilitators, speech and language therapist, activity and residential support staff, home managers and 24/7 care provisions.

- Ethical permission was granted by the Health Research Authority to conduct research with people with learning disabilities. In order to gain approval reasonable adjustments were made to inform potential participants about the study, request consent and collect data. Pictorial formats were used for consent forms, invitation sheets and food frequency questionnaires. A video was also produced to explain what would happen if they chose to participate in the study and to explain their rights. This was regarded as best practice given that many of the service users approached could not read and therefore easy read formats would not be appropriate to explain complex information in order to gain informed consent.

- Discourse with individuals with a learning disability enabled valuable information and understanding. This learning informed the recommendations from the study.
The opportunity to present issues that people with learning disabilities experience at forums for Primary Healthcare Practitioners (including GPs and Associate Physicians), highlighted the need for further training, and for recommendations to be developed regarding the organisation of such events.

Lay report.

Summary

Individuals with a learning disability are more likely to be overweight than people who do not have a learning disability. The literature shows that people with learning disabilities are more likely to have an increase in obesity-related health conditions (Van de Louw et al, 2009). The Dietary Approaches for Metabolic Syndrome, Obesity and improved Nutrition for people with learning disabilities (the DAMSON project) aimed to provide resources and train staff to support people with learning disabilities to make healthy food choices and to reduce the risk of obesity and associated health conditions.

The training and resources were evaluated using a pretest-posttest research design. The training was perceived to impact staff knowledge, attitudes and behaviour but delegates had perceived the training to have less of an impact on the wider staff team and management. Following the provision of the resources and workshop being provided to staff, individuals with learning disabilities consumed more vegetables but no other significant changes were found with regards to their eating habits.

The journey and what we learnt along the way.

Before developing appropriate resources that encourage individuals with a learning disability to prepare and eat healthy foods, it was important to engage with individuals with learning disabilities and the staff that supported them. A local specialist school for children with learning disabilities agreed for the principle investigator to attend cooking sessions and meet with the staff and students. This opportunity provided valuable insight in the challenges the project team would face when developing resources but also provided potential solutions for making the resources more accessible and appropriate. Suggestions from staff included ensuring that personal hygiene and cross-contamination were considered at the start of each cooking session, recipe and during the cooking activity. As a result, videos
available on each recipe page included a reminder for people to wash their hands. In addition, videos to prompt washing utensils following touching specific foods that may cause foodborne illnesses were included in the recipe instructions.

Two cooking sessions were observed, the first group of students made banana cake and in the second session they made chocolate cake. The principle investigator was informed that parents liked their children to bring home cakes and desserts as these were easily shared, while meals were not large enough to share with the family. This highlighted the importance of training sessions to include discussion on how healthy meals can be shared with family members in the format of a taster, a side dish or even a starter.

During the school cooking session, instructions were verbally presented using simple language. This was supported by the teacher writing the ingredients on the board and encouraging people to count or weigh ingredients together. However, this support may not always be available. For example, adults with learning disabilities who live independently with a limited number of hours of staff support, would not have this support available to them while preparing a meal. Therefore, the project team decided to use pictures and audio recordings to provide this information in the cookbook and used every-day utensils to weigh ingredients.

A Heritage to Health event enabled the principle investigator to observe individuals with learning disabilities following an easy read cooking recipe. This observation highlighted a number of challenges with easy read formats. For example, using photographs only provided individuals with information about a snapshot in time, which they then have to interpret. This led to confusion, as illustrated in the examples of zesting an orange and kneading bread (see box 1). This indicated the importance of using a series of real-time visual examples that people can follow.

**Box 1.**

Scenario 1: An individual was presented a photo of a grater and an orange with a small amount of orange zest, with the caption “grate the skin of the orange”. The individual began to grate the whole orange, including the rind, seeds, and juice.

Scenario 2: As one person was completing a task from the instruction sheet it was noted that other budding cooks copied their action, even if it was incorrect or did not match the photo or instructions in front of them.
Procurement of resources to support the training and video were purchased. This included plates showing portions of vegetables, protein and carbohydrates in pictorial format, in line with the eatwell guide. The eatwell guide is a tool used to define government recommendations on eating healthily and achieving a balanced diet (Public Health England, 2018), it represents the recommended quantity of what we should consume from each food group to achieve a healthy balanced diet. In addition, resources were provided such as packet of seeds to grow vegetables, strawberry shaped shopping bags, and cooking timers with coloured stickers to enhance the understanding of how long food needs to be cooked for. The latter was felt important as many individuals with learning disabilities do not have a good concept of time and find it difficult to read and interpret clocks (Faragher and Clarke, 2013).

Following from the creation of the cookbook and procurement of resources, a one-day training workshop for staff was developed (see lesson plan in Appendix 1). The workshop covered the following topics:

1. How to identify metabolic syndrome (combination of diabetes or pre-diabetes, high blood pressure and obesity)
2. Educating individuals about healthy eating and food cultures
3. Changing environmental practices and supporting change.
The workshops were designed to encourage participation through using scenarios, practical tasks and reflection on own practices, and aimed to encourage staff to develop ideas which they could implement in their practice. Individuals with learning disabilities who contributed to the cookbook joined us for lunch during the workshops. This provided the opportunity for them to talk to staff about their experience of making the videos. Individuals with learning disabilities who attended the workshops also talked to staff about their feelings about healthy eating and what others can do to support them. Following the workshops, staff were asked what additional materials or information they would find helpful to support them in their roles. This further informed the training section included in the online cookbook.

A number of different avenues were used to promote the workshops. The workshop events were advertised through social media and websites. In addition, training departments for NHS Trust across Kent, Surrey and Sussex were approached and agreed to inform their staff about the training opportunity through their local intranet pages. Word of mouth (from other delegates and prospective delegates) as well as advertising through the training departments appeared to have had the greatest response. However, many of the delegates who registered to attend were unable to partake on the day.

As a result of the workshops two common issues were reported regarding the quantity of snacking and portion control. Staff felt that they provided nutritious meals but issues arose due to additional snacks purchased by service users. In terms of portion control, practical examples taken from the nudge approach was used to enable discussion around these issues, for example, explaining how using smaller plates and different sizes of drinking vessels could support appropriate portion sizes. Nudge is a concept which proposes positive reinforcement and indirect suggestion to influence people’s behaviour and the decisions that they make, to encourage them to make healthy choices.

To consider the effectiveness of the resources and workshop delivered, it was felt important to evaluate the impact on individuals with a learning disability. Ethical approval was gained from the Health Research Authority to do a pilot study with participants who had learning disabilities. A number of reasonable adjustments were required to the documentation which were essential to gain ethical approval for the research project. Firstly, the information sheet was created in video format. All potential participants viewed the video which supported them to make a decision with regards to participation. Secondly, the consent from, invitation sheet and questionnaires were written in easy read and staff supported potential participants to read these. Finally, the information regarding General Data Protection Regulations
(GDPR, 2018) were provided as an audio recording and in print, so that individuals could access this information as frequently as they wished.

Following training delivered to staff, provision of the resources and raising awareness of the online cookbook, participants with learning disabilities seemed to have similar food patterns, weight, BMI, waist circumference and diastolic blood pressure. The post-test results of the study showed that individuals did eat more vegetables and had lower systolic blood pressure. Due to the small sample size and short duration of the intervention (8 weeks), conclusions and recommendations need to be made with caution.

Qualitative feedback and informal discussions when taking measurements from participants highlighted a number of areas that are worthy of further exploration. This includes comments regarding how eating fruit and vegetables stems from being encouraged to eat these as a child, how eating fruit is associated with healthy activities such as playing sport, and how individuals found it easier to increase steps per day than to resist food which they considered to be the ‘naughties’.

Observations and comments from staff supporting individuals who were present during the data collection although not formally recorded were significant. In one home staff had produced a wall display highlighting some of the information that was discussed in the workshop to disseminate the learning to colleagues and service users. However, in other homes staff commented how they had been unable to attend the training, so they were not sure what recommendations or approaches they should use. This shows that a disparity in dissemination to colleagues was evident, and further consideration of how to ensure training is passed on to other members of the team to enable consistency is required.

Box 2: Sample of comments from qualitative feedback

“Trying to watch my portion size … I ask the staff about smaller plates to make it look bigger than it actually is”

“Been eating nice things …like vegetables, peas, carrots, not cauliflower because cauliflower doesn't agree with my stomach.”

“Cutting out more naughties like cheese savouries, as like those, so say cut it out now.”

“I’ve cut down on the sugar. I used to have about three, you know, now I’ve cut that down to two. Yeah so I’ve cut down a little bit.”
The final component of the project involved training staff who work in General Practice (GP) surgeries. Despite 19 staff being registered to attend the one hour workshop, only 5 were able to attend, due to last minute changes to the timings of the event. This meant that one of the two sessions had to be cancelled because the actors with learning disabilities were unable to stay. Lessons were learnt from these circumstances by the project team. Firstly, it is important to inform the event organisers of the specific needs of people with learning disabilities and / or autism, especially when they are presenting at the conference. Staff who are supporting people with learning disabilities to co-facilitate training, need to ensure that event organisers and hosts of training events, are aware of any reasonable adjustments beneficial for the co-presenters. Secondly, staff working in GPs require further knowledge and support with regards to communication with people with learning disabilities and applying reasonable adjustments for their patients with learning disabilities.

**Recommendation**

1. Increase support for people with learning disability for healthy eating, through educating staff around food cultures and nudge techniques.
2. Continue delivery of training to raise awareness of metabolic syndrome, how to identify it and evidence based interventions to support care delivery.
3. Enable a wider group of service users to contribute to the cookbook, and to ensure sustainability of the cookbook as a freely available resource.
4. Promote dissemination of the cookbook to individuals with learning disabilities, staff, parents and carers.
5. Further training involving individuals with learning disabilities as co-facilitators for staff working in the primary care sector.
6. Provide resources and training within specialist schools to encourage healthy eating from an early age.
7. Support researchers and people with learning disabilities to engage with each other to support their agendas and build knowledge and skills in provision of reasonable adjustments as per ethical requirement.
8. Disseminate the work through HEEKSS to inform workforce development.
9. Provide information to hosts and event organisers regarding the needs and preferences of people with autism and/or learning disabilities.
10. Identify the most effective means to embed research and new knowledge within the healthcare workforce.

References
