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# Developing and implementing dietary interventions for people with learning disabilities: reflections and advice.

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# Abstract.

Individuals with learning disability are more likely to have poor dietary habits and associated health conditions than the general population. Interventions to support improving dietary choices need to consider reasonable adjustments to enable resources to be accessible to people with learning disabilities. A multi-level approach including development of resources and training for staff is reflected on, to share learning experiences and tips for professionals working in this area.

#### Best Practice.

- Use of reasonable adjustments to support people with learning disabilities to access and apply health promotion resources.
- Collaborate with people with learning disabilities, staff and carers to support the design and implementation of interventions.
- Use real-time visual prompts to guide skill development and decision making.
- Liaise with training event organisers about the specific needs of co-presenters with learning disabilities and/or autism.

## **Background.**

This paper aims to add to the knowledge base relating to developing and implementing dietary interventions for people with learning disabilities. Previous studies have developed unique weight loss interventions and adapted existing interventions, however, the wider context of people's lives has reduced the effectiveness of such interventions (Croot et al., 2018; Roberts-Mitchell, 2014). Therefore, understanding contextual issues and further insight regarding the reasonable adjustments that can be considered in the design and implementation of healthy eating initiatives will be discussed.

### Dietary intake in people with a learning disability.

The diets of individuals with a learning disability are more likely to be inadequately balanced in comparison to a typical dietary pattern of individuals who do not have a cognitive impairment (Hamzaid et al., 2019). The impact of an inadequately balanced diet is dehydration and malnutrition, which have been associated with an increased morbidity and mortality in people with learning

disabilities (Kolset et al., 2018). In addition, balanced dietary intake has the potential to reduce the risk of non-communicable diseases (WHO, 2011). Therefore, the World Health Organisation supports the need to improve nutritional intake in individuals with a learning disability.

Individuals with learning disabilities are more likely to be malnourished (lacking sufficient nutrients for optimum health) than the general population (Franssen et al., 2011) as their diets are lower in essential micronutrients, whole-grains, fruit and vegetables (Hamzaid et al., 2019; Ptomey et al., 2013). In samples of people with learning disabilities from different countries micronutrient intakes of magnesium, calcium, iodine, zinc and vitamin A, D and E were deficient, (Hamzaid et al., 2019; Ptomey et al., 2013; Hoey et al., 2017). However, sodium levels exceeded the recommended upper limit due to a high intake of processed meats, bread and pre-prepared meals (Hamzaid et al., 2019).

Individuals with learning disabilities have been found to eat less than 1.5 portions of fruit and vegetables a day (Hamzaid et al., 2019). Fruit and vegetables contain a rich source of fibre, antioxidants and phytochemicals, which support good health. Phytochemicals from fruits and vegetables have potential beneficial effects on human health, which may be a therapeutic tool to manage diseases (Vacca et al., 2016).

#### Causes of poor dietary intake.

Malnutrition can be caused by oral motor difficulties such as dysphagia, frequent choking episodes, gastro-oesophageal reflux disease, dental issues, food allergies, medication side effects and specialised diets (Gibson et al., 2011; Grumstrup and Demchak, 2019). Dysphagia is a reduced capacity to chew and swallow, which may require the texture of foods to be modified (Hamzaid et al., 2019). These conditions are all found at increased prevalence in individuals with a learning disability. Furthermore, multimorbidity is common in people with learning disability with a large UK based study reporting that 98.7% of 1023 people with learning disabilities reported two or more physical health conditions with a mean of 11 conditions per participant (Kinnear et al, 2018). Prevalence rates of health concerns above the level found in the general population have been reported with 31-41% found to have obesity, 25% dysphagia and 33.8% constipation (Tyrer et al., 2019; Kinnear et al, 2018).

Caregivers report that the availability and accessibility of food are the most important determinants of nutritional status of individuals with learning disabilities (Ruud et al., 2016). Therefore, to increase the consumption of healthy foods, these foods need to be readily accessible through close proximity and in a form that is easy for the individual to eat.

Further explanations for the poor diet of individuals with learning disabilities are supported in the literature, and include poorer health literacy, reduced knowledge about nutrition, reduced skills in food preparation, increased food fussiness, and greater reliance on others to provide nutritional requirements (British Dietetic Association, 2011; Hoey et al., 2017; Bandini et al., 2019). Social and environmental factors influencing dietary intake related to reliance on others include availability, and accessibility of food and caregiver preferences and knowledge around food. Furthermore, medical reasons and personal preference can impact the dietary intake of individuals with learning disabilities, and can make it challenging to change existing dietary patterns in this population (Grumstrup and Demchak, 2019).

Further research is required to gain insight into the feasibility of enhancing a nutritionally-balanced diet to support optimum health in individuals with learning disabilities. Interventions are required to support individuals with learning disabilities who have poor dietary habits, with lower intakes of fruit, vegetables and micronutrients. Current understanding of the reasons for the poor nutrition

among individuals with learning disabilities is complex and requires a multifaceted approach, incorporating their wider social networks.

A Health Education England funded research project was undertaken to evaluate the impact of a dietary intervention for people with learning disabilities who had some of the symptoms of metabolic disorder. This paper reflects on the lessons learnt while implementing the interventions

## The interventions.

Two interventions were implemented. Firstly, online resources were produced for people with learning disabilities to support them when preparing healthy meals. This included a real-time cookbook that people with learning disabilities could follow to encourage them to try a variety of fruit and vegetables whilst applying safe practices. The cookbook is available at <a href="https://canvas.kingston.ac.uk/courses/12067">https://canvas.kingston.ac.uk/courses/12067</a>.

Secondly, training was provided to staff who support people with learning disabilities. The training focussed on metabolic syndrome and interventions or strategies that staff can use to encourage a healthy dietary pattern in their service users. More information about the project can be found on Health Education England's workforce development pages for Kent, Surrey and Sussex at https://idhekss.wordpress.com/reports/a-z/#OBE. The training focussed on the following approaches being applied to dietary choices:

- Nudge behavioural science theory (cognitive, affective and behavioural nudges that can guide people's choices towards a healthier option)
- Social learning theory (role modelling and reinforcement)
- Mere exposure theory (Repeated exposure, stimulus recognition, convenience, availability and accessibility).

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. The Nudge approach which uses a combination of food availability, positive reinforcement and indirect suggestions to influence decision making, is gaining support within the literature to improve lifestyle behaviours within both institutional work and school settings (Williamson et al, 2013). Cognitive nudges include using symbols to indicate healthy options and placing healthy foods at eye level, affective nudges include describing foods using appetising terminology to draw attention to healthy options. Finally, behavioural nudges include placing healthy vegetables at the start of the buffet, smaller plates, larger glass sizes to keep people hydrated and making it easier and more convenient to take the healthy option (for example placing chopped crudités and fruits close by and chocolate at the back of the kitchen cupboard).

## Researcher's Reflections on the learning journey.

The learning that took place by the researcher can be categorised in the following areas: lessons learnt relating to the development of the resources and lessons learnt relating to the provision of training to support changing dietary habits. These two areas are important to advance evidence-based changes to practice and are discussed in detail.

#### Development of resources.

Insight on the effectiveness of nutritional interventions for people with learning disabilities was gained from patient and public involvement (PPI) activities, involving people with learning disabilities in the development of the online cookbook and the research project. PPI included attending and facilitating cooking sessions and speaking with staff and service users from a variety of settings.

Videos, cookbooks and easy read leaflets which aim to support people to cook often fail to adequately address risks associated with personal / environmental hygiene and cross-contamination. While providing feedback on the resources that were developed as part of the project, staff expressed that they felt that handwashing should be prompted at the start of each cooking session. In other resources reviewed, the importance of handwashing was highlighted on earlier pages on the website or in a book however this information would be forgotten at the time when people with Learning Disabilities prepare their meals. Furthermore, staff perceptions revealed that healthy foods presented in the resources contain some high risk ingredients. For example, chicken is used less while cakes and biscuits are preferred as these are deemed safer. Therefore, a reminder for people to wash their hands before starting food preparation and videos to prompt washing utensils following touching specific foods related to foodborne illnesses were included as part of the recipe instructions in all the resources. Individuals with learning disabilities reported that they liked the idea of an online cookbook and expressed meals that they felt should be included within the cookbook. A number of individuals expressed that they would like to be involved with creating the cookbook for their peers to follow.

Observations from a facilitated cooking session using an easy to read information sheet with simple language and pictures highlighted a number of challenges for people with learning disabilities. One observation related to the use of photographs. Photographs present a snapshot in time, which people have to interpret. It was observed that this was difficult for some people. For example, when the picture showed how to grate an orange, people attempted to grate the entire orange, rather than just the skin of the orange. This indicated the need for using real-time visual examples that are broken down into simple steps that people can follow.

Needing to cook food for the required length of time was also something that needed careful consideration, given that uncooked chicken and turkey can harbor salmonella. Many people with learning disabilities find estimating the time that has lapsed, reading clocks and setting alarms difficult. Therefore, a system to support people who are unable to count was required, and a kitchen timer which used colours rather than numbers presented a possible solution. This enabled people to match colours with those on the photographs and this also was well received by staff who were able to see multiple uses of using this technique both inside and outside of the kitchen.

Finally, including people with learning disabilities while cooking the meals, which were used as video explanations of the steps to make the meal, challenged attitudes and practices. Individuals with learning disabilities being observed cooking Christmas dinner challenged the notion that their abilities require the need to restrict what food preparation they can engage with. It follows that individual assessments on safe use of knives, ovens and other equipment and adapting activities according to individual abilities and needs encourages independence and learning.

#### Provision of training.

It is well documented in the literature that in order to change behaviours and dietary practices it is important to work with the individual, their support staff and at an organisational level (Giraud-Saunders and Marriott, 2016). Training for staff included one-day workshops and conference

presentations. Participants with learning disabilities who co-produced the cookbook attended the workshops during the working lunch session. This enabled staff to see how nudges could be used in practice and also enabled them to informally chat with individuals with learning disabilities about healthy eating, cooking and staring in the videos. During the mealtime individuals expressed how they was proud to have cooked a whole meal and to have helped with the project, how they find it hard when tempted by unhealthy snacks but liked the food on offer during the event.

During the workshops two common issues were reported regarding the quantity of snacking and portion control. Staff reported that they provided nutritious meals but additional snacks were purchased by service users, snacks were deemed as adding to the daily calorie intake but lacking beneficial nutrients. The workshops highlighted the benefit of using nudges as a behavioural change approach. In terms of portion control, practical nudges were 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 with large cups for water and small cups for fruit juice. Following staff implementing nudges, one service user with a learning disability found this to be particularly helpful as noted in his comment:

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

Participants reported that they found using smaller plates for meals, smaller portions, linking healthy snacks with activities such as football, and being taught about healthy eating as a child to get into a good routine early in life beneficial for healthy eating. Furthermore, individuals acknowledged that staff motivating them through having successes (such as weight loss or choosing healthy options) recognised and setting achievable goals were supportive to adopt healthier eating. While the consistency of fruits that are not cooked, feeling like eating junk food when sad and temptations in shops being a deterrent to healthy eating.

Organising and presenting at a conference for general practitioners and staff working in the primary care sector was a valuable learning opportunity both for delegates and for the research team. Copresenters who have learning disabilities were invited to the event early so that they could familiarise themselves with the room, wider environment and meet the other speakers. The event was designed as a workshop to enable active engagement with people who have a learning disability. The reflection completed after the conference event related to audience participation and unplanned changes on the day of the conference, the changes were not foreseen but required alterations to the room and time of the scheduled conference presentation. Forewarning event organisers of the impact these changes could have on the guest speakers with learning disabilities and/or autism may have negated room changes and thus reduced levels of anxiety. Delegates appeared to find conversations difficult for a number of reasons, including staying on topic (which would be gained through increasing joint attention through easy read assessments and materials), confidence in discussing plans and finding out about people with learning disabilities' perspectives and daily lives. Therefore, in retrospect from reflections on these events a number of learning can be shared. Firstly, it is important to inform the event organisers of the specific needs and any reasonable adjustments of the people with learning disabilities and / or autism, especially when they are co-presenting or co-facilitating at the conference. Secondly, staff working in GP surgeries require further knowledge and support with regards to communication with people with learning disabilities and applying reasonable adjustments for their patients with learning disabilities.

## Conclusion.

People with learning disabilities have dietary patterns that often lack essential nutrients. Adjusting our usual ways of working in consideration of the needs and wishes of people with learning disabilities is essential to support successful implementation of interventions that promote people with learning disabilities to engage in healthy lifestyles.

Reasonable adjustments are required to support people with learning disabilities to make healthy dietary choices, to inform the development of resources, to co-facilitate training and to have them participate in research. This article has provided a number of adaptations that can be considered when implementing training programmes and conducting research to promote well-being in people with learning disabilities.

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