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# **Portfolio of Doctorate in Health Psychology**

## **Addressing Health Inequalities in Disadvantaged Groups using Health Psychology Theory and Evidence**

**By Kiran K Bains**

**For the qualification of Professional Doctorate in  
Health Psychology**

**School of Health Sciences  
City, University of London**

**April 2019**

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## **DECLARATION**

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## **ABBREVIATIONS**

BCT – Behaviour Change Taxonomy

LD: Learning Disabilities

LGBTQ – Lesbian, Gay, Bisexual, Transgender, Queer/Questioning

NCF – Necessity-Concerns Framework

MVPA – Moderate to Vigorous Physical Activity

SCT – Social Cognitive Theory

T2DM – Type 2 Diabetes Mellitus

TDF – Theoretical Domains Framework

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## LIST OF PUBLICATIONS

Bains, K. K. (2017). Integrating health psychology theory and research with health education and training for adults with learning disabilities in healthy eating, physical activity and sedentary behaviour, *Journal of Health Psychology and Public Health*, 1(2). Last accessed on 30.04.17 from [www.hpphn.org.uk/275/Integrating-health-psychology-theory-and-research-with-health-education-and-training-for-adults-with-learning-disabilities-in-healthy-eating-physical-activity-and-sedentary-behaviour](http://www.hpphn.org.uk/275/Integrating-health-psychology-theory-and-research-with-health-education-and-training-for-adults-with-learning-disabilities-in-healthy-eating-physical-activity-and-sedentary-behaviour)

Bains, K. K. (2019). Finding a suitable placement for entry into a Professional Doctorate or Stage 2 Training equivalent, in Walton, H. (Ed.), *A guide for psychology postgraduates: surviving postgraduate study* (2<sup>nd</sup> Ed.). British Psychological Society: UK. Last accessed on 19.04.19 from <http://www.psypag.co.uk/psypag-guide/>

Bains, K. K. & Turnbull, T. (2019). Attending the Creative Knowledge Mobilisation workshop at DHP Conference 2018: A review, *Health Psychology Update*, 28(1), 43-44. Last accessed on 19.04.19 from <https://shop.bps.org.uk/publications/health-psychology-update-vol-28-no-1-spring-2019.html>

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## **SECTION A: PREFACE**

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### **Addressing Health Inequalities in Disadvantaged Groups using Health Psychology Theory and Evidence**

This portfolio focusses on work undertaken to aid understanding and reducing health inequalities in several underserved minority groups. The main topic was health promotion with adults with learning disabilities using theory and evidence-based approaches. A social cognitive theory-based interview study was conducted with adults with learning disabilities and carers to better understand how the model could be used to address healthy eating, physical activity and sedentary behaviour in this group. This led to planning, development and delivery of a health promotion intervention in group and individual settings, primarily focussing on healthy eating as this was identified as a key priority. One of the group interventions has been the focus of the case study for the behaviour change intervention competence. The research undertaken also informed teaching sessions with social care staff to enhance practical and emotional social support provided to clients.

In contrast, the consultancy project involved delivering a public health intervention with United Kingdom (UK) Punjabi South Asian adults regarding prevention and management of Type 2 diabetes on the radio. This involved increasing understanding and coping with diabetes, behaviour change to enhance lifestyle management and provide mutual positive social support within the community and changing beliefs regarding medical decision making. Finally, the systematic review was conducted in the field of LGBTQ (Lesbian, Gay, Bisexual, Transgender, Queer/Questioning) health. This focussed on psychological barriers to primary care access faced by adults self-identified as sexual or gender minorities under this umbrella term.

#### **Research Thesis**

Social cognitive theory-based interviews were carried out with adults with mild-moderate learning disabilities and their carers to understand healthy eating, physical activity and sedentary behaviour within this group. This aimed to inform future intervention development using this approach with adults with mild-moderate learning disabilities. The rationale,

method and findings will be outlined, and the findings situated in the context of the wider literature.

## **Publications**

Integrating health psychology theory and research with health education and training for adults with learning disabilities in healthy eating, physical activity and sedentary behaviour (500 words).

Finding a suitable placement for entry into a Professional Doctorate or Stage 2 Training equivalent (2843 words).

Attending the Creative Knowledge Mobilisation workshop at DHP Conference 2018: A review (750 words)

Submitted for publication:

Barriers to Equitable Primary Healthcare Access experienced by LGBTQ adults for general health issues: A systematic review (5916 words).

## **Professional Practice**

### **Consultancy**

A series of radio talks were delivered with a South Asian audience on Type 2 diabetes prevention and management, underpinned by Levanthal's' Self-Regulatory Model, Bandura's' concept of Collective Efficacy, and techniques from the Behaviour Change Taxonomy by Michie and colleagues.

### **Behaviour Change**

The behaviour change intervention involved using a social cognitive theory-based approach to promote healthy eating, physical activity and reduce sedentary behaviour with a group of adults with mild learning disabilities.

### **Teaching and Training**

Teaching and training workshops were conducted with adults with learning disabilities on how they could improve their diet, physical activity levels and reduce sedentary behaviour. I also taught staff how they could promote healthier eating with clients more effectively.

## **Systematic Review**

The systematic review focussed on barriers to equitable primary care access faced by LGBTQ (Lesbian, Gay, Bisexual, Transgender and Questioning/Queer) adults for general physical health problems using the Theoretical Domains Framework. Six studies were found, reported in seven research papers, the vast majority focussing on experiences of LGB adults. The most frequently endorsed barrier domains were skills, social and professional roles and identities, beliefs about capabilities and social influences. This was linked to issues of systemic heterosexism in healthcare contexts, which impacted trust and communication with primary care professionals. This in turn was associated with poorer self-reported general health status by LGB (Lesbian, Gay and Bisexual) adults.

## References

- Cane, J., O'Connor, D., & Michie, S. (2012). Validation of the Theoretical Domains Framework for use in behaviour change and implementation research. *Implementation Science*, 7(1), 37. 10.1186/1748-5908-7-37
- Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F. et al. (2011). *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews*. Department of Family Medicine, McGill University: Retrieved from <http://mixedmethodsappraisaltoolpublic.pbworks.com>

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## **SECTION B: RESEARCH**

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### **Conducting Social Cognitive Theory-Based interviews with adults with mild-moderate learning disabilities and carers to understand healthy eating, physical activity and sedentary behaviour in this population**

#### **Abstract**

Adults with mild-moderate learning disabilities tend to have poorer diets, lower levels of physical activity and higher levels of sedentary behaviour than adults in the general population (Dunkley, Tyrer, Gray, Bhaumik, Spong et al., 2017; de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012). Despite this, there are relatively few studies exploring perspectives of this group and their carers on these behaviours and what may help promote health behaviour change in this group. The current study used social cognitive theory (Bandura, 1986; Bandura. 2001) based interviews with 24 participants, 12 adults with mild-moderate learning disabilities and 12 carers. This explored their understanding of these behaviours and how interventions using the model could be implemented more effectively in future. Role modelling and recognition of achievement were important to improve self-efficacy in initiating healthy eating and physical activity. Proxy efficacy was also important for adults with learning disabilities to allow staff to make important related decisions for them. Immediate hedonic response was also important in considering outcome expectancies of eating behaviours and activities adults with learning disabilities chose to engage in. In addition, the main sources of social support were from carers and peers and could be both positive and negative. This impacted goal setting, planning and behaviour change approaches. Finally, carers had varied depth of understanding of the nature of sedentary behaviour and how this could be reduced with adults with learning disabilities. The feasibility and limitations of theory-based interviewing will be discussed and implications for future health promotion interventions.

# Introduction

## Background

### **1.1 The health of adults with learning disabilities: rates of overweight, obesity and underweight in comparison to adults in the general population and associated risks for their health**

Previous research has established that adults with learning disabilities may have greater rates of obesity and underweight than adults in the general population (Bhaumik, Watson, Thorp, Tyrer, & McGrother, 2008; Dunkley, Tyrer, Gray et al., 2017; McGuire, Daly, & Smyth, 2007; Mikulovic, Vanhelst, Salleron, Marcellini, Compte et al., 2014). This is especially so for those with mild-moderate learning disabilities (de Winter et al.; Stancliffe, Lakin, Larson, Engler, Bershinsky et al., 2011). This group may also be at risk of malnutrition (Koritsas & Iacono, 2016; Tsai, Hsu, & Chang, 2011) and associated poorer quality of life.

Overweight and Obesity is particularly associated with increased risk of conditions such as Type 2 diabetes in adults with learning disabilities and adults in the general population (Cooper, McLean, Guthrie, McConnachie, Mercer, Sullivan et al., 2015). With improvements in medical care over time for the general population, adults with milder learning disabilities may also have increased longevity. They may also become at increased risk of mortality from preventable or 'lifestyle diseases' such as cardiovascular disease and certain cancers.

### **1.2 Factors which may explain why adults with mild-moderate learning disabilities may be more at risk of overweight, obesity and overweight which may not be modifiable**

Adults with learning disabilities may be more likely to have other physical health issues to be considered when promoting health in this group especially if they have other impairments, which may be related to the underlying cause of their learning disability. Adults with Downs' syndrome, for example, often have congenital heart defects as a result of their condition (Krahn & Fox, 2014). One large study found adults with Downs' syndrome were also substantially more likely to be overweight or obese than those without (MacRae, Brown, Karatzias, Taggart, Truesdale-Kennedy et al., 2015). Furthermore, adults with learning disabilities are more likely to take '*obesogenic*' medication for other associated conditions. Epilepsy, mental health disorders and challenging behaviour are more prevalent and

psychotropic and anti-epileptic medications are commonly prescribed in various combinations to this cohort (Hler, Thome, & Reis, 2015; Hsieh, Rimmer, & Heller, 2014). They may also be more likely to have poorer health due to factors associated with generally having low socio-economic status (SES) relative to adults in the general population (Emerson, Hatton, Baines, & Robertson, 2016). Emerson et al. (2016) assessed this with the estimated '*hidden majority*' of adults with mild learning disabilities not known to specialist services. They found that material and social deprivation, an unsafe environment and low income can negatively impact on their participation in healthy eating, physical activity and sedentary behaviour (Emerson et al., 2016). This contributes to increased rates of overweight, obesity and underweight in this population. It is thought this also applies to those with a learning disability diagnosis receiving formal support as few are in employment and many receive benefits in the United Kingdom (Rodgers, 1998; Smyth & Bell, 2006). Adults with learning disabilities overall are on par with adults in the general population in England (Hosking, Carey, Shah, Harris, DeWilde et al., 2016). Nevertheless, this analysis masks the wide variation between the health behaviours of adults with mild-moderate learning disabilities and those with severe or profound learning disabilities.

### **1.3 Behaviourally modifiable factors which may explain why adults with mild-moderate learning disabilities may be more likely to have overweight, obesity and underweight than adults in the general population**

Diet, physical activity and sedentary behaviour play a key role in explaining the high levels of overweight and obesity amongst adults with learning disabilities found in various studies earlier on in this review. Dunkley, Tyrer, Gray et al. (2017) found that less than a third ate five or more portions of fruit and vegetables a day. Just over a third of their sample also either walked short distances or not at all, versus sixty four percent that walked '*some*' or '*lots*'. Finally, around half in total reported sitting most or all day sitting down. They did not break this down according to level of learning disability and mobility of participants.

Dairo, Collett, Dawes, & Oskrochi (2016) found those with severe or profound learning disabilities were significantly less likely to meet physical activity guidelines than those with milder learning disability. This was potentially due to lack of understanding and greater physical impairment, though only 9% overall met these guidelines. Whereas de Winter et al. (2012) examined the health of older adults with learning disabilities in a social care context.

They found the following participants were at higher risk of obesity and overweight: participants with milder learning disabilities; autism; able to eat independently; prepare meals and shop for groceries independently and those that were physically inactive. Furthermore, having a lower level of learning disabilities, being able to eat more independently and shop for groceries independently were all factors associated with greater risk of obesity versus overweight. However, these factors were inter-related with each other, so may overlap in causal explanation for this finding. Finally Melville, Oppewal, Elinder, Freiburger, Guerra-Balic et al. (2017) found that adults with learning disabilities spent more time engaging in sedentary behaviour than adults in the general population. In addition, a greater proportion of their leisure time was spent with activities such as watching television and using ‘*passive transportation*’ such as private transport rather than active methods such as walking to activities (Messent, Cooke, & Long, 1998).

#### **1.4 The benefits of promoting healthy eating, physical activity and reducing sedentary behaviour in adults with mild-moderate learning disabilities**

Healthy diets are rich in mono-unsaturated fats (Willett, 1994), a variety of vegetables, fibre (Orenstein, Chetrit, & Dankner, 2016), fish, nuts, legumes, plant and seafood protein, low or no-fat dairy, low in trans and saturated fats and refined sugars (de Ridder, Kroese, Evers, Adriaanse, & Gillebaart, 2017; Onvani, Haghghatdoost, Surkan, Larijani, & Azadbakht, 2017). These ingredients are thought to promote good health and reduce morbidity and mortality from cardiovascular disease and certain cancers (Onvani, Haghghatdoost, Surkan, Larijani & Azadbakht, 2017). A healthy diet is also protective against certain common mental health issues such as depression (Rahe, Unrath, & Berger, 2014). It is unclear if fruit should be considered healthy, as they often contain high amounts of sugar, particularly derivatives such as juice.

In contrast an unhealthy diet is generally considered to involve low intake of vegetables, fibre, nuts, whole grains along with high consumption of red meats, trans and saturated fats, processed foods, sweetened drinks, products with added salt and sugar and alcohol (Onvani et al., 2017). The ‘*western diet*’ as it is often known has been associated with increased overweight and obesity, blood pressure, incidence of Type 2 diabetes, heart disease, certain cancers and mental health issues (Onvani et al., 2017; Orenstein et al., 2016; Willett, 1994; Wirt & Collins, 2009).

Adults with learning disabilities, particularly those with moderate-severe learning disabilities or adults with Downs' syndrome, may sometimes be more likely to suffer from constipation and acid reflux (Böhmer, Klinkenberg-Knol, & Niezen-de Boer, 2002; Böhmer, Taminiu, Klinkenberg-Knol, & Meuwissen, 2001; Wallace, 2007). A healthy diet may help prevent and manage these issues through provision of increased fibre, managing portion size, alcohol intake and monitoring fat intake in the diet (Kubo et al., 2014).

Increasing moderate to vigorous physical activity (MVPA) may also be beneficial in Type 2 diabetes prevention (Aune, Norat, Leitzmann, Tonstad, & Vatten, 2015; Harrington et al., 2016; Yates, Davies, & Khunti, 2013) and management (Umpierre et al., 2011; Yates, Khunti, Troughton, & Davies, 2009). This can improve cardiovascular health with a curvilinear dose-response effect (Loprinzi, 2015). A recent study by Loprinzi, Addoh & Mann (2017) found that this also applies to adults who may have mobility problems and are therefore less able to take part in aerobic exercise. Those of their participants participating in muscle-strengthening exercise sessions more than two times a week in line with US health guidelines (U.S. Department of Health and Human Services, 2008) reduced their relative risk of all-cause mortality by 33-38%. However, this also depended on their level of functional impairment. A systematic review by Bartlo & Klein (2011) also identified that adults with learning disabilities improved their balance, muscle strength and quality of life after taking part in physical activity interventions in comparison to controls.

Physical activity may also be protective against major depression and some anxiety disorders (Goodwin, 2003). A longitudinal study by Hiles, Lamers, Milaneschi & Penninx ((2017) established that greater levels of sports participation may reduce odds of having anxiety and depression two years later in a general adult population. They also found sport and physical activity participation may reduce risk of continued anxiety and depressive disorders in those who may have it at an earlier time point. This relationship was bidirectional: higher levels of anxiety and depression at an earlier time point predicted lower sports participation, specifically, at later time points.

Sedentary behaviour is thought to be distinctly different to physical activity (Sedentary Behaviour, 2012; Tudor-Locke & Myers, 2001). Sedentary activities are defined as those using  $1 \leq$  METS (Metabolic Equivalent) of energy and/or involve sitting and lying down (Sedentary Behaviour, 2012). This includes screen-based time, television viewing, reading,

sitting in classes, occupational sitting time and sedentary forms of transport. These may all be regular activities for adults with mild-moderate learning disabilities (Melville et al., 2017). A person can be quite sedentary for most of their day despite taking part in MVPA (Ku, Fox, & Chen, 2016) and the relationship between the two is quite weak (Jakes, Day, Khaw, Luben, Oakes et al., 2003; Owen, Leslie, Salmon, & Fotheringham, 2000). Sedentary behaviour also has its' own distinct effect on weight gain (Thorp, Owen, Neuhaus, & Dunstan, 2011; Tremblay, Colley, Saunders, Healy, & Owen, 2010), diabetes risk (Proper, Singh, van Mechelen, & Chinapaw, 2011; Wilmot et al., 2012), mortality risk from cardiovascular disease, cancer and all causes (Proper et al., 2011; Thorp et al., 2011; Tremblay et al., 2010; Wilmot et al., 2012), separate to that of physical activity, particularly in women. Hiles et al. (2017) found participants with lower levels of sedentary behaviour were less likely to have continued anxiety and depression at a later time point. A high proportion of time spent watching television has also been associated with increased risk of mental health issues in young adults (Tremblay et al., 2010), though this may need further investigation as social isolation, for example, may also play a role. Hiles et al. (2017) also found those with comorbid anxiety and depression showed increased sedentary behaviour at follow up than healthy controls, supporting this idea.

### **1.5 The current context of health provision in the UK: The use of health checks**

Adults with learning disabilities are now offered annual health checks in primary care in the UK. This can lead to earlier identification of chronic conditions, low engagement with health promoting behaviours and weight management issues, creating opportunities for timely prevention and management of health concerns (Robertson, Hatton, Emerson, & Baines, 2014). This needs to be met with sufficient availability of theory and evidence-based interventions to address these issues, particularly for those adults with mild-moderate learning disabilities.

### **2.1 Key health behaviour change models and their usefulness for understanding and influencing healthy eating, physical activity and sedentary behaviour, and the rationale for using a social cognitive theory approach**

Numerous social cognition models have been created to understand the health beliefs and behaviour of the general population and the basis for decision making in relation to this. As a

result, there have also been numerous constructs thought to underpin behaviour change (Cane, O'Connor, & Michie, 2012). Individual variables impacting behaviour change by adults with learning disabilities include socio-demographic variables, personality, learning disability, affect and cognitions. Social and environmental influences include social support, built environment, accessibility and measures taken to incentivise certain behaviours on a larger scale (e.g. subsidising sports facilities). Most psychologists have focussed on individual factors, primarily cognitions, and to a lesser extent, social support to understand decision making by individuals regarding their health. These are more proximal influences on behaviour and may mediate the relationship between wider social determinants and health, such as socio-economic status. Therefore, they are a logical focus for health interventions (Conner & Norman, 2015). There have been many models posited over time to explain health behaviours, but we will outline a few of these as they were considered widely influential in the field (e.g. Conner & Norman, 2015; Ogden, 2007).

The first, protection motivation theory (Maddox & Rogers, 1975) addresses fear appeals as a method of persuasive communication to engender behaviour change. The first component; threat appraisal, incorporates an evaluation by the individual about the severity of a threat (e.g. the severity of the consequences of heart disease). The second aspect is the individual's perception of their vulnerability to that threat (e.g. by appraising their current diet, and the likelihood of having heart disease). The third element is the individual's coping appraisal based on their perceived response efficacy. This is the evaluation of the likelihood that a certain course of action can remove the threat, such as following a healthy diet to prevent illness and their sense of self-efficacy in carrying this course of action out. This model, however, neglects the role of social influences, which may be an important consideration for adults with learning disabilities (Kuijken, Naaldenberg, Nijhuis-van der Sanden & van Schrojenstein-Lantman de Valk, 2016).

The second, the theory of planned behaviour (Ajzen, 1991) suggests proximal determinants of behaviour are attitude, subjective norms, perceived behavioural control and intentions to carry this behaviour out. A person's attitude toward a certain behaviour and the subjective norms they have about this due to the social influences of others are thought to influence behaviour indirectly change through their impact on intentions. Perceived control over behaviour can also have direct impact on behaviour and an indirect impact through influencing intentions to change behaviour. For instance, if they have a positive attitude

toward physical activity, supported by subjective norms that value this and believe they have greater control over their exercise behaviour, their intention to be physically active will be stronger. This is thought to translate to increased physical activity.

This does not, however, account for the importance of practical and emotional social support for adults with learning disabilities in performance of activities of daily living. Nor does it account for the influence of the physical environment on their abilities to carry out certain behaviours. This is also important as they are more likely to have physical impairments which can compromise their ability to navigate facilities to eat healthily or participate in physical activity (Bergström, Hagströmer, Hogberg, & Elinder, 2013) than adults in the general population. These two theories also assume that decision-making is a rational process where individuals weigh up the pros and cons of their actions before deciding a course of action to take. This can be unrealistic as hedonic impulses and notions of meaning ascribed to health behaviour, including food consumption, can have a significant influence on the actions carried out by people (Luomala, Hellén, & Jokitalo, 2018). Adults with mild-moderate learning disability additionally may have memory and cognitive difficulties that can compromise this decision making process (Smyth & Bell, 2006).

The third theory, self-determination theory (Deci & Ryan, 2000) focusses on what may influence motivation. This is posited to be influenced by three over-arching factors: autonomy, competence and relatedness. Autonomy is defined as the ability of the person to exercise their free will, competence defined as the ability to perform a specific action and relatedness defined as how a certain behaviour will influence their relatedness with significant others. It is included here because the notion of autonomy is important to adults with learning disabilities (Smyth & Bell, 2006). Relatedness may also be an important construct as their carers and peers may have a strong influence on their decision making (Kuijken et al., 2016). The drawback here is that it is primarily a theory of motivation, rather than considering explicitly the wider social and environmental contexts that may play a role in behaviour change, or what may help a person achieve their goals in the face of obstacles (Hagger & Chatzisarantis, 2015). Regardless of this, it has led to important work on goal-setting as people may set goals to achieve mastery in a particular area, such as cooking, or the avoidance of losing previously acquired skills (e.g. memory and cognition). They may additionally set performance-oriented goals to demonstrate their competence to others or to avoid failure or perceived incompetence by others (Elliot & McGregor, 2001).

People with learning disabilities may at times be under greater pressure than most to demonstrate independence and pass as *'normal'* in wider society, as a stigmatised minority. The people supporting them may also feel the need to co-construct this *'normality'* (Smyth & Bell, 2006) and set performance related goals to demonstrate competence rather than focus on actual mastery. This also highlights that the nature of goals set is important to behaviour change. This is also a key construct in social cognitive theory, which we will now turn to.

## **2.2 A focus on social cognitive theory and reasons for using it to understand the engagement of adults with mild-moderate learning disabilities with health behaviours, and how to use the underlying constructs in the theory as mechanisms of action to promote health behaviour change in this group**

To fully capture understanding of health behaviours of adults with learning disabilities with regard to healthy eating, physical activity and sedentary behaviour, social cognitive theory (Bandura, 1986; Bandura, 2001) was chosen as an appropriate guide. Social cognitive theory posits that behaviour is driven by self-efficacy, outcome expectancies, social support and more general barriers and facilitators according to the personal, social and environmental contexts individuals operate in.

Self-efficacy, often considered a key construct underpinning behaviour change in its' own right (Conner & Norman, 2015) is an individuals' expectation that they can perform a particular behaviour, adjusting their efforts to overcome difficulties or obstacles to achieve a desired outcome. This is a realistic appraisal of capability and is related to self-confidence (Cane et al., 2012). However, it is difficult to improve a person's' sense of self-efficacy but doing so is related to greater desired health behaviour change (Conner & Norman, 2015). Greater self-efficacy can firstly, be achieved through enactive mastery, whereby a person gains knowledge and skills through direct experience. Secondly, it can increase via provision of informative feedback, to aid development of competence when developing skills. Thirdly, through vicarious learning through observing role models in the environment and finally, via verbal persuasion to increase belief in the ability to reach a realistic improvement in performance (Bandura, 1986; Bandura, 2001).

Outcome expectancies are defined as what a person may expect to be the consequence of a particular course of action if they carry it out (Bandura, 2001), such as praise and recognition

(Bandura, 1986). These can be positive or negative and involve both affect and cognitive appraisals. Social support, likewise, can be positive and help enable behaviour change or it can be negative and impede them in carrying out health behaviours. Social cognitive theory also incorporates goal setting and self-monitoring. Proximal goals tend to be short-term, concrete and have more observable outcomes, whereas distal goals are long-term, tend to be more abstract and have less tangible outcomes. Finally progress in attaining these goals is monitored throughout the process and over time to self-regulate the goal-oriented behaviour and adjust these if necessary.

Social cognitive theory (Bandura, 2001) was chosen as an appropriate model firstly because self-efficacy as a construct has been associated with greater fruit and vegetable intake and uptake of nutritionally healthier behaviour in various populations (Conner & Norman, 2015). It has also been linked with initiating and sustaining exercise (Luszczynska & Schwarzer, 2015). Indeed, the evidence to support the influence of self-efficacy on behaviour is robust enough that a theory of self-efficacy has been created in its' own right (Self-Efficacy Theory, Bandura, 1986). It is self-regulatory in nature (Bandura, 1986; Luszczynska & Schwarzer, 2015) and thus may be difficult for a person with a learning disability to achieve as they may struggle to master appropriate skills to drive healthier eating and physical activity without considerable support. It is important to ascertain which strategies from self-efficacy theory may help this group improve their mastery and coping with temptations to eat unhealthily (Bandura, 1986).

The second reason why social cognitive theory was used in this study was that proxy efficacy could be a potential key influence on behaviour of adults with learning disabilities (Bandura, 2001). Making healthy lifestyle choices can involve understanding details such as nutrition content of food and long-term consequences of behaviour, thus this may be considered a somewhat complex process. Adults with learning disabilities sometimes rely on their primary carers to make health-related decisions for them due to their cognitive limitations (Smyth & Bell, 2006). They also rely on carers to provide effective emotional and practical support to understand the importance of health promoting behaviour and how to implement this. Under what conditions proxy efficacy and social support may be provided optimally needs to be examined in greater detail for this population.

Factors that enhance carer self-efficacy to support healthy eating, physical activity and reduction of sedentary behaviour in this group also need to be understood, particularly in the sometimes challenging environments they work in (Cartwright, Reid, Hammersley, Blackburn & Glover, 2015; Cartwright, Reid, Hammersley, & Walley, 2017; O'Leary, Taggart, & Cousins, 2018; Rodgers, 1998; Spanos, Hankey, Boyle, Koshy, Macmillan et al., 2013). Additionally, it is important to learn what outcomes may be important and desirable from the perspective of adults with learning disabilities and their carers regarding healthy eating and nutrition. Moreover, constructing an understanding of positive and negative sources of support for this group can create opportunities for future intervention development. This includes sharing good practice and providing training and support to adults with learning disabilities and carers to address negative support.

It would also help to know what can be helpful when goal setting is used in relation to health promotion interventions for this group, with regards to goal complexity and duration as cognitive ability and memory may impact this. Finally, it is also important to account for what may facilitate and impede healthy eating, physical activity and reducing sedentary behaviour. This study aims to increase understanding how to tailor future healthy eating, physical activity and sedentary behaviour interventions to the needs of adults with mild-moderate learning disabilities using a social cognitive theory-based approach.

### **3.1 Previous lifestyle interventions carried out with adults with mild-moderate learning disabilities and their carers around healthy eating, physical activity and sedentary behaviour**

A growing body of literature documents the interventions carried out with adults with mild-moderate learning disabilities to help them eat more healthily and increase their physical activity. There is also increasing interest in understanding and decreasing sedentary behaviour in this group, but this research is still in its' infancy (Melville, Oppewal, Elinder, Freiburger, Guerra-Balic et al., 2017). These aim to help reduce the significant health inequalities that adults with learning disabilities face (Krahn & Fox, 2014) by promoting health, preventing illness and aiding management of long-term conditions that involve lifestyle change. They are also important for this vulnerable group as poor health can compound the adversities that adults with learning disabilities may already face. This includes the discrimination and stigma associated with having a learning disability (Emerson et al., 2016) and how these in turn also constrain their upward '*social mobility*' and the

opportunities they can access (Emerson et al., 2016). Previous interventions have used a variety of approaches, some of which were theory based whilst others were not. Some of these programmes have involved primary carers whilst others have not. As a result, perhaps unsurprisingly, they have had mixed results.

Evidence based interventions designed to promote healthy eating and physical activity to adults with learning disabilities have used several different approaches. Most focussed on weight management (Bergström et al., 2013; Chow et al., 2016; Marks, Sisirak & Chang, 2013; Marshall, McConkey, & Moore, 2003; Melville et al., 2011; Spanos, Hankey, & Melville, 2016) due to higher rates of overweight, underweight and obesity in this group relative to the general population. Prevention or management of '*lifestyle diseases*' has also been a key aim, such as Type 2 Diabetes (Bazzano et al., 2009; Dunkley, Tyrer, Doherty et al., 2017). A systematic review by Willems et al. (2017) looked at use of behaviour change techniques in lifestyle interventions for adults with learning disabilities aiming to increase healthy eating and/or physical activity in this group. Interventions frequently used instruction, practice, planning for social support, advice on consequences and goal setting. It is not yet established whether some other behaviour change techniques are suitable for this group due to their complexity (Willems et al., 2017). Certainly increasing self-efficacy can be difficult to achieve (Conner & Norman, 2015), but key to enabling behaviour change in the general population. They also found that whilst most used similar techniques in their interventions, few employed a complete theoretical framework to underpin their intervention.

Some health promotion interventions have been underpinned by social cognitive theory (Bazzano et al., 2009; Bergström et al., 2013; Chow et al., 2016; Marks et al., 2013; McDermott, Whitner, Thomas-Koger, Mann, Clarkson et al., 2012), but their implementation of this theory has varied. Chow et al. (2016) used goal setting and modelled exercise behaviours for adults with learning disabilities to improve their self-efficacy and provided staff training to increase positive social support. However, they also appeared to include a component from the Theory of Planned Behaviour (Ajzen, 1991), as their intervention was also partly based on this, having adapted a protocol from Bodde, Seo, Frey, Lohrmann & Van Puymbroeck (2011).

Bazzano et al. (2009), used peer mentoring as a key component of their programme, to promote development of self-efficacy and positive social support through role modelling from peers with mild-moderate learning disabilities. A facilitator from the research team also

assisted in the intervention. Whereas Bergström et al. (2013) created the role of health ambassador amongst staff teams they worked with and facilitated development of a peer learning circle amongst staff with regular support from the research team. This aimed to enable peer role modelling and social support amongst staff. They also had group classes amongst adults with learning disabilities to facilitate peer support amongst users, though they noted peers at times made negative and discouraging comments. Carers provided individually tailored support and praised clients, facilitating engagement with novel activities and foods, possibly by improving their self-efficacy. They also reduced barriers to participation by adapting to users' physical needs, including food sensitivities and physical impairments. Similarly Marks et al. (2013) trained staff to deliver a healthy eating and physical activity programme to individual clients based on the transtheoretical model and social cognitive theory. They aimed to help them work with clients to identify benefits of healthy eating and physical activity (outcome expectancies), increase self-confidence and perceived social support. To an extent they were able to improve self-efficacy and perceived social support of end users with learning disabilities post-intervention, though it was unclear how staff achieved this.

McDermott et al. (2012) used social cognitive theory in a large randomised trial with adults with learning disabilities, in the most methodologically robust study to date. They delivered group health education sessions on healthy eating and physical activity to the intervention group whilst controls participated in a matched placebo on hygiene and safety. Both groups showed evidence of healthier behaviours at end of the intervention and twelve-month follow up, but the results did not differ significantly between both groups. They incorporated instruction and peer social support from Social Cognitive Theory (Bandura, 2001) but did not aim explicitly to improve self-efficacy of participants.

Finally Perez-Cruzado & Cuesta-Vargas (2016) implemented a physical activity intervention based on social cognitive theory with forty adults in a pre-post intervention study, though they also did not explicitly aim to improve self-efficacy. Instead they relied on education and professionally led physical activity sessions with users to indirectly achieve this outcome. However, Perez-Cruzado & Cuesta-Vargas (2016) did aim to engage users in improving support provision by others to be active outside the session and there was a significant relationship between self-efficacy and family support. There was also a significant relationship between family, peer and professional support, but no other variables significantly related to self-efficacy. This may also be in part due to the relatively small sample size. It is also important to note they only included those able to read and write, which

can exclude a significant proportion of adults with mild-moderate learning disabilities. Neither does this necessarily relate well to their understanding and participation in activities or verbal communication skills.

It is also unclear from previous interventions what outcomes were important to the people with learning disabilities themselves. Most researchers focussed on weight and disease related outcomes for the users of their interventions to motivate them to participate. They also adapted their resources to this group, to improve accessibility and understanding, used 'concrete' examples and repetition (Bazzano et al., 2009; McDermott et al., 2012; Melville et al., 2011). This, however, neglects the perspectives of adults with learning disabilities and their carers in the process. There is previous research to suggest adults with learning disabilities are interested in discussing their own health and participating in intervention development (Dunkley, Tyrer, Doherty et al., 2017; Rodgers, 1998; Young & Chesson, 2008).

#### **4.1 Previous studies examining the understanding of adults with mild-moderate learning disabilities and carers about what constitutes healthy eating, physical activity and sedentary behaviour**

Previous research by Caton, Chadwick, Chapman, Turnbull, Mitchell et al. (2012), Dunkley, Tyrer, Doherty et al. (2017), Kuijken et al. (2016) and Young & Chesson (2008) suggests adults with learning disabilities have some understanding of what constitutes a healthy diet. Participants suggested eating fruit and vegetables, fish, pasta, and salad, drinking fluids, particularly water, and avoiding fatty and sugary foods were key to health (Caton et al., 2012; Kuijken et al., 2016). They also suggested that healthier cooking methods, eating regularly and having unhealthy foods in moderation were helpful (Caton et al., 2012; Kuijken et al., 2016).

Conversely, apparent understanding of actual health benefits varied significantly as some suggested it was important because '*it was good for you*' whilst others were able to link healthy eating with prevention of '*lifestyle*' illnesses (Caton et al., 2012). Some participants also talked about healthy eating to avoid weight gain and promoting weight loss. Evidently weight concern was clearly an important issue for these participants (Caton et al., 2012). Additionally Kuijken et al. (2016) identified that confusion about how to implement a healthy diet seemed common, firstly, due to misinterpretation of public health messages. For

example, one participant thought that choosing an appetiser or dessert in a meal was a necessity to get nutrients rather than to limit indulgence. Confusion was also caused by changes in nutrition guidelines over time conveying the impression that almost everything was unhealthy and how to moderate intake of unhealthy food.

Previous research with adults with learning disabilities also suggests that they had some awareness that physical activity is important for health. Participants particularly identified walking and sports as beneficial (Caton et al., 2012; Kuijken et al., 2016). Participants interviewed by Dunkley, Tyrer, Doherty et al. (2017) stated that walking was also a preferred form of activity for them though they specifically interviewed those with a BMI of  $>25\text{kg/m}^2$  with impaired glucose tolerance. These individuals may struggle to perform more vigorous activities.

There has been some research into what carers believe are important factors that influence healthy eating and physical activity by adults with learning disabilities (Rodgers, 1998; Spanos et al., 2013). However, little research has examined knowledge that care staff have of what constitutes a healthy diet or active lifestyle generally (Melville et al., 2009) or for preventable diseases (Hanna, Taggart, & Cousins, 2011; Trip, Conder, Hale, & Whitehead, 2016).

Previous studies indicate carers had some knowledge of health promoting behaviours though in most cases it did not specifically related to public health guidelines (Melville et al., 2009). Additionally staff were given very little training (Hanna et al., 2011; Trip et al., 2016), some stating they obtained their knowledge from clients with intellectual disabilities themselves (Trip et al., 2016). However, there was little difference in knowledge between trained and untrained care staff (Hanna et al., 2011). There has also been very little research in this area with family carers (Rodgers, 1998). There has also been no research, to this authors' knowledge, looking at carers' knowledge of what constitutes sedentary behaviour. Given difficulties researchers have had distinguishing between insufficient physical activity and sedentary behaviour in this population, this may not be surprising (Melville et al., 2017). However, the most endorsed benefits of healthy eating stated by carers surveyed in Melville et al. (2009) were disease prevention, overall improvement of health and quality of life (72-95%). Less than half believed it would help adults with learning disabilities live longer or lose weight effectively. For physical activity the perceived benefits most endorsed was the impact on general health and quality of life (80-92%). Approximately half also believed it

would aid disease prevention, longevity and weight management, though very few participants believed a healthy diet or physical activity would help adults with learning disabilities look slim and feel attractive. This may reflect what carers think is important or achievable by their clients, but it is important to note the researchers set the parameters of what outcomes could be achieved by adults with learning disabilities living healthily. It is unclear whether they considered what may be important outcomes to their clients. However, Kuijken et al. (2016) conducted a study with adults with learning disabilities and they identified that feeling healthy and being independent was important to wellbeing. They also suggested that what constitutes healthy living is also driven by individual needs, such as allergies. This echoes the findings of Bergström et al. (2014) who observed that efforts carers made to tailor the intervention to individual needs of their clients was key to successful implementation of the intervention.

#### **4.2 Previous research on factors that impact healthy eating and physical activity in adults with learning disabilities**

There have been several studies examining what influences healthy eating and physical activity of adults with learning disabilities, at times involving perspectives of adults with learning disabilities and carers themselves. Several mentioned the importance of intrapersonal factors: they felt the level of understanding of the people with learning disabilities varied greatly regarding healthier diets and physical activity levels and its' benefits. This impacted their motivation and engagement in health promotion through having a shortened attention span, poor memory and difficulties weighing information about long term consequences of a poor diet and low levels of activity (e.g. Bergström, Elinder, & Wihlman, 2014; Mahy, Shields, Taylor, & Dodd, 2010; Smyth & Bell, 2006; Spanos et al., 2013). This also impacted their understanding of how to adhere to a healthier lifestyle, including development of cooking skills and participation in physical activity (Spanos et al., 2013). Physical impairment also played a role in this (Bergström et al., 2014), particularly for older adults, as they were concerned about risks of falling when going out to be active (Dixon-Ibarra, Driver, Vanderbom, & Humphries, 2017). The presence of poor physical health and co-morbid health conditions could also make it more difficult, especially in participating in physical activity (Mahy et al., 2010; Stancliffe & Anderson, 2017).

Alternatively, adults with learning disabilities were more likely to take part in physical activity if they enjoyed it, won awards for participation or if the activity fulfilled an interesting purpose, such as helping others (Dixon-Ibarra et al., 2017; Mahy et al., 2010; van Schijndel-Speet, Evenhuis, van Wijck, van Empelen, & Echteld, 2014). Adults with learning disabilities interviewed by Caton et al. (2012) also attributed experiencing stressful events as a barrier to move toward healthier living, suggesting that they may have coping difficulties.

Adults with learning disabilities often face significant intrapersonal barriers so tend to rely on support from others to engage in daily activities. The support they get from carers, whether paid or unpaid (namely family), can therefore play a role in their participation in healthy eating and physical activity. Yet this is not always available. Indeed, Stancliffe & Anderson (2017) surveyed over eight thousand adults with learning disabilities and found adults with milder learning disability either able to exercise alone, with housemates or co-workers were significantly more likely to meet US guidelines for moderate physical activity than if they relied on a carer for support. At times these factors doubled their odds of sufficient participation in physical activity. Barriers in support were commonly included a lack of availability and access to healthy foods and little to no involvement by adults with learning disabilities in shopping and cooking. Added to this was a lack of support to go out to take part in physical activity (Dixon-Ibarra et al., 2017; Mahy et al., 2010; van Schijndel-Speet et al., 2014). At times carers perceived that it was unsafe for some clients to go out in wider communities and access opportunities by themselves, for example if they had poor road sense (Caton et al., 2012).

#### **4.3 Previous research on impact of carer knowledge, attitudes and experience with health promotion on healthy eating, physical activity and sedentary behaviour of adults with learning disabilities**

Staff knowledge and interest in healthy living can also play a key role in client engagement in healthy eating and physical activity, as positive role modelling, encouragement and enthusiasm could be infectious (Caton et al., 2012; Dixon-Ibarra et al., 2017) but so could disinterest. Indeed as Kuijken et al. (2016) noted, adults with learning disabilities they interviewed seemed to be strongly influenced by their carers and peers perceptions. Smyth & Bell (2006) noted that staff working with adults with learning disabilities themselves also tended to come from lower socio-economic status backgrounds. They argued that as a result,

many of them may not have had much opportunity to choose healthier foods or activities for themselves, which would influence the choices they presented to their clients.

Another key issue, particularly for paid staff working with adults with learning disabilities, is apparently a dilemma between what they perceive to be their professional duty of care and enabling their clients to freedom of choice (Smyth & Bell, 2006; Spanos et al., 2013). Thus, some carers would accept whichever choices a person they supported made, whereas others would suggest it was staffs' responsibility to promote healthier choices amongst their clients (Spanos et al., 2013). There are different understandings of choice, but as Smyth & Bell (2006) suggest, for adults with learning disabilities this can be influenced by familiarity, past experiences of making choices and to what extent their choices are accepted, choice complexity and previous opportunities to try novel foods and activities. Therefore, making choices is a complex issue with social elements.

Another study by Pelletier & Joussemet (2017) gave adults with learning disabilities an unpleasant task and examined the influence of communication style on persistence and their perceived value of the task. When experimenters used an empathic, non-judgmental approach, neutral, non-controlling language (i.e. steps in the task rather than what they would have to do next), gave participants simple choices and created reasonable boundaries and expectations they made greater effort and saw the task as more valuable. This could be applied to perseverance with health promotion, as at times it may be difficult for them to maintain a healthy diet and higher levels of physical activity. Carers have been found to vary in how well they can teach the people they support, for example in presenting healthier alternatives or supporting clients to assert their needs more to others (Smyth & Bell, 2006). Beyond this, carers may also have limited cooking skills, and certainly for paid staff, there may not be much training available to do this (Caton et al., 2012). Working well together with other carers, particularly for paid carers in staff teams, may help address this. Smaller, stable staff teams with a consistent approach, good communication and a shared motivation to help clients to change behaviour in care services has been perceived as important (Spanos et al., 2013). This could be made difficult if working with other agencies or carers, including day centres, that do not also support clients with healthy living, by frequently visiting fast food places or not providing active pursuits (Messent et al., 1998; Spanos et al., 2013). A lack of support from managers or at organisational levels was also another factor. Other barriers to healthy living in this group include poor staffing, cancelled fitness sessions, shift instability

resulting in carers not having enough time to plan menus or ensure others followed care plans (Dixon-Ibarra et al., 2017; Mahy et al., 2010; Ruud, Raanaas, & Bjelland, 2016; Spanos et al., 2013; van Schijndel-Speet et al., 2014). Indeed Ptomey, Gibson, Lee, Sullivan, Washburn et al. (2017) found greater turnover in '*study buddies*' for participants in a weight loss intervention resulted in smaller weight loss over time.

Wider social or environmental influences on healthy eating, and arguably to a greater extent physical activity, include access to opportunities to improve healthy living, such as availability of specialist transport. This particularly impacts those with limited mobility (e.g. Caton et al., 2012). Experience of stigma in wider society (Mahy et al., 2010) and social pressure on adults with learning disabilities to appear knowledgeable and independent can compound these influences. These factors can create difficulties in providing appropriate support (Smyth & Bell, 2006) and in the current UK context barriers to physical activity may also be exacerbated by closures of day services for adults with learning disabilities.

Matthews, Mitchell, Stalker, McConnachie, Murray et al. (2016) noted service closures could be disruptive to routine and put additional pressures on day staff and family carers to find alternatives for the people they support. They found this was a key barrier to uptake of their physical activity intervention and commented that some learning disability walking groups had also disbanded as a result.

#### **4.4 Gaps in our understanding of factors that may help adults with learning disabilities with healthy eating, physical activity and sedentary behaviour to develop future social cognitive theory-based interventions with this group**

There are currently few studies exploring carers' knowledge of healthy eating and physical activity and none exploring their awareness or knowledge of sedentary behaviour. There are also relatively few in depth qualitative studies with carers and most of these have focussed on barriers and facilitators to health promotion amongst adults with intellectual disabilities, but there are several gaps. Firstly, several studies focussed on barriers and facilitators experienced by adults with learning disabilities as a group rather than specifically those with mild-moderate learning disabilities (Cartwright et al., 2015; Cartwright et al., 2017; O'Leary et al., 2018; Rodgers, 1998; Spanos et al., 2013). As stated earlier, adults with mild-moderate learning disabilities are particularly vulnerable to overweight and obesity, and poorer diets. Those with greater severity of learning disability are also more vulnerable to lower physical

activity participation (Stancliffe & Anderson, 2017), so this is not to argue further investigation is not warranted with this subgroup, but that further research would benefit from greater specificity in understanding the needs of this diverse cohort.

Secondly, very few have recruited family and informal carers; most of these have sampled paid staff (Bergström et al., 2013; Cartwright et al., 2015; Dixon-Ibarra et al., 2017; Melville et al., 2009; O’Leary et al., 2018; Rodgers, 1998). It’s important to understand differences in understanding of health behaviours, perspectives of how this can be addressed and whom may be responsible for instigating change (Cartwright et al., 2017).

There are also very few qualitative research studies exploring the perspectives of adults with mild-moderate learning disabilities on their health, despite evidence suggesting they are interested in discussing their health needs (Young & Chesson, 2008). One study interviewed older adults (Van-Schijdel-Speet et al., 2014) so it is unclear whether this can be generalised to a younger cohort; particularly as several participants suggested playing games was ‘immature’ in relation to physical activity for their age. Another recruited via a self-advocacy and quality assurance group of adults with learning disabilities (Caton et al., 2012) to explore depth of understanding regarding healthy eating and physical activity. This may be potentially problematic if they are more able than their wider cohort, more articulate or more engaged with these topics. The final study explored the understanding of adults with mild-moderate learning disabilities in the Netherlands regarding healthier lifestyles and factors which impact this from their perspective using focus groups (Kuijken et al., 2016). However, aside from potential differences in data generated due to group dynamics and potential consensus effects, generalisability to other cultural contexts is unclear and this needs to be replicated and developed further. This is because to this authors’ knowledge, a theory-based approach interview study to understand what could aid development of health promotion interventions with this cohort has not been previously conducted with adults with mild-moderate learning disabilities. Yet, this may be important to assess whether it is possible to, for example, increase self-efficacy in this group as this is presently unclear as it is a complex construct and can be difficult to achieve in the general population (Connor & Norman, 2015; Willems et al., 2017). It may also help to assess whether theory-based interview research is feasible with this group and what steps could aid their participation as it involves discussion of potentially complex constructs within health behaviour models.

Likewise, there has only been one study conducted with carers using a theory-based approach on the topic of health promotion with adults with learning disabilities (O’Leary et al., 2018) and this differs in several ways. It only recruited paid staff in a social care context, focussed

on adults with learning disabilities as a cohort and used the transtheoretical model to understand barriers and facilitators to health promotion on an organisational level. The current study aimed to involve paid and family carers, focussed on adults with mild-moderate learning disabilities and used social cognitive theory to aid understanding and development of individual and group level behaviour change interventions with this group. Social cognitive theory was chosen because this model accounted for social and environmental factors which can play a key role in health behaviour uptake in this population, high self-efficacy is thought to be important to increase uptake in many health promoting behaviours and goal setting is a key element of the theory (Bandura, 1986; Bandura, 2001). Goal setting may also be familiar to some adults with learning disabilities, particularly those in social care, as it is often part of person-centred planning with this group. Finally, social cognitive theory was chosen as it has informed several previous behaviour change interventions with adults with learning disabilities, more so than the transtheoretical model, but this research aimed to support development of interventions that are theory-based and thus improve their implementation.

Understanding perspectives of adults with mild-moderate learning disabilities and carers on how the constructs in social cognitive theory can be used as the underlying base for a health behaviour change intervention is important to tailor this to the needs of this group. This includes what outcome expectancies are important to them, how self-efficacy might be improved in this group and their carers, sources of positive and negative support and how to set goals and monitor progress in a way that is meaningful to them. The current study aimed to address these questions and inform development of healthy eating, physical activity and sedentary behaviour interventions for adults with mild-moderate learning disabilities.

#### **4.5 Current study objectives**

Given the identified gaps in the literature above, the current study aimed to investigate the following:

- 1) How adults with mild-moderate learning disabilities and carers conceptualised healthy eating and physical activity.
- 2) How carers conceptualised sedentary behaviour and their awareness of this term as distinct from physical activity.
- 3) What participants thought could help adults with mild-moderate learning disabilities to increase uptake of healthy eating and physical activity and to decrease sedentary behaviour.

- 4) To use social cognitive theory as the underpinning framework for designing the interview guide and analysis of data.

## **Methodology**

### **5.1 Participants**

Participants were carers (paid and unpaid) and managers of care services and adults with mild-moderate learning disabilities adults using support services aimed at this group.

### **5.2 Inclusion/exclusion criteria**

Adults with learning disabilities needed to be 18 years or older, able to give informed consent and sufficiently able to communicate verbally, using pictorial aids if appropriate, to be eligible for participation. Exclusion criteria included being mainly or exclusively non-orally fed, having a terminal illness.

Carers needed to have at least three months experience supporting a person with a mild-moderate learning disability as well as to have last provided support within the previous three months. They also had to be in a role where they were directly or indirectly involved in supporting an adult with mild-moderate learning disabilities on a regular basis, as a paid or voluntary carer, a relative, or manager of a day or care service.

### **5.3 Sampling**

Participants were recruited via the researcher's professional and personal contacts within a social care organisation. Other professionally linked local organisations were also approached in West London which provided day services, social care, education and advocacy for adults with learning disabilities and their parents. Recruitment aimed to be purposive, in that it involved carers in a variety of settings and roles in caring for adults with learning disabilities, striving for an even split of managers, support workers and family members. We also aimed to interview participants with a diverse mix of age, race, educational backgrounds and length of experience supporting people with learning disabilities to increase representativeness of

the sample, however most carers were professional contacts of the author so were self-selecting for interview, which may limit generalisability (7 staff, two family carers). For adults with a learning disability, participants with a range of learning disability severity were sought. However, this had to be balanced with time and resource constraints and a certain degree of convenience sampling took place. Three participants with learning disabilities had had prior contact with the researcher but none were receiving support services from the author as this represented a conflict of interest. Participants also tended to have mild learning disability and good verbal communication skills.

#### **5.4 Informed consent**

To facilitate gathering of informed consent with adults with learning disabilities, a staged consent process was used with potential participants. Organisations and services were contacted and given easy read and supplemental care information about the study to briefly explain what this involved to their service users. The researcher then visited the services if participants showed interest, to explain the study in more detail, introduce themselves and build rapport and trust. The researcher emphasised the optional nature of participation with potential participants and explained that they could ask for a carer to support them to participate if they wished. Any supporting staff were offered reimbursements for their time and consent processes were in place to ensure they were not coerced into a supporting role in interviews with adults with learning disabilities. However, the adults with learning disabilities who participated in this study all chose to participate independently. For some, their preferred carers were not available to provide support during interview, but they wished to participate regardless of this. This was respected by the researcher as they had made an informed choice to proceed with participation.

Where also appropriate, the researcher conducted mental capacity assessments with potential participants based on the Mental Capacity Act (2005) after an initial meeting. This was used to ascertain whether they were likely to understand what was involved in the study, process of participation and their right to withdraw from the study. Where there were concerns, the author also discussed participation in the study with carers or staff who knew these individuals well, to ascertain whether they would likely understand what was involved and be able to provide informed consent. Consequently, two adults learning disabilities was not approached further by the researcher as they were unlikely to have the capacity to provide informed consent according to staff whom worked closely with them.

For adults with learning disabilities who demonstrated mental capacity to make an informed decision regarding research participation and agreed to interview, the author explained the study again at the beginning of the session. An easy read consent form was also used to structure this and provide appropriate detail, which was then signed by participants and the researcher. However, trust and rapport were also essential to minimise power imbalances between researcher and participant as much as possible (Sigstad, 2014) and discreet continuous monitoring by the researcher to check for verbal and non-verbal signs of discomfort or distress from participants. Where observed, this was addressed with participants and comfort breaks were given where requested or deemed appropriate by the researcher. This applied to interviews with adults with learning disabilities as well as interviews with carers. Several adults with learning disabilities chose not to participate in the study after care staff had explained to them what was involved at the initial stage of the process. One participant with a learning disability also terminated his interview early after discussing healthy eating with the researcher as he no longer wished to participate. Though this can be generally disappointing for researchers, in this case it provided reassurance that the process of supporting staged and continuing consent was effective in minimising risk of coercion to participate in research with this vulnerable group and their carers.

## **5.5 Measures**

Participants were also asked about their age, gender and ethnicity. Carers were asked about their highest educational attainment level, the role in which they supported a person with a learning disability, whether they were a primary carer and length of experience. Adults with learning disability were asked about the identity of their primary carer and their main sources of support for daily living activities. Their level of learning disability and communication methods were also recorded. This was discussed prior to participation where appropriate with a carer that knew them well.

Participants with learning disability were given a short quiz devised by the author to ascertain their food and physical activity preferences and assess for social desirability bias, as this can be particularly prevalent in this group (Sigstad, 2014). To minimise these biases, building trust, rapport and a use of a non-judgmental manner by the researcher were also crucial to convey the importance of authenticity over acquiescence to the perceived desires of the researcher. Participants were given a forced choice of 3 alternatives and asked to rank them

from favourites to least favourite (5 food and drink choices, 15 items total; 4 activity choices, 12 items total). Food choices were grouped by category (snack, beverage, main meal, accompaniment) and the number of healthy and unhealthy alternatives was kept consistent across items (e.g. fruit, crisps and chocolate for one item; water, hot chocolate and fizzy drinks for another). Activity choices were also grouped in a similar manner with one example of physical activity given, alongside two sedentary alternatives (e.g. going for a walk versus watching TV and listening to music in a chair). The choices taken were then measured for internal consistency to cross-validate their interview data for authenticity.

## **5.6 Interview guide**

The interview guide was developed by the author, with close reference to the study aims and Bandura's Social Cognitive Theory (Bandura, 1986; Bandura, 2001). Each question was explicitly associated with the specific construct it aimed to focus on (e.g. knowledge, outcome expectancies, self-efficacy). The latter also applied to the vignettes which were developed to aid '*concreteness*' and simplify concepts as appropriate for participants with intellectual disabilities. These were designed by the author and based on their extensive experience providing support services to this group in a variety of social care and independent living contexts. The vignettes were also available for carers to facilitate discussion of sensitive issues whilst protecting confidentiality of the people they supported and this was highlighted at the beginning of their interviews.

All participants were interviewed about their knowledge of what healthy eating and physical activity involves. Carers additionally were interviewed about their definition of sedentary behaviour, including whether and how they would differentiate it from physical activity.

Participants were then interviewed about their perspective on healthy eating and physical activity using Social Cognitive Theory as the underlying framework (Bandura, 1986; Bandura, 2001, see Appendix A). They were asked what adults with learning disabilities might gain from it, as well as their motivations for engaging with this (outcome expectancies). Questions were also designed to probe what would aid their self-efficacy at improving and maintaining health promoting behaviours in these areas in the face of obstacles and carer self-efficacy at engaging their service users in these areas. This particularly focussed on challenging behaviour and barriers people with learning disability may face in engaging with these issues. Vignettes were also used to aid understanding and

engagement where appropriate and all aimed to probe only into the construct intended (Johnston, Dixon, Hart, Glidewell, Carin et al., 2014; Appendix B).

As carers also sometimes make decisions for people they support in these and related areas as a proxy, factors that assist sense of proxy efficacy by adults with learning disabilities towards their carers were also examined (i.e. willingness to allow them be a proxy decision maker in certain areas). We discussed the role of social support (positive and negative) and other barriers and facilitators to engaging in these behaviours (personal, social and environmental factors). Finally, we talked about what could be helpful when setting goals and monitoring progress, planning and influence of past and current behaviour in terms of diet, activity and sedentary behaviour.

## **5.7 Ethics**

The study was given ethical approval by the School of Health Sciences Ethics Committee, City, University of London (reference: DPsych/16-17/01).

## **5.8 Data collection**

Adults with learning disabilities were involved in the steering group for the research study and gave feedback on study invitations, consent forms, measures and picture aids prior to data collection. The mental capacity assessment devised by the author was also checked independently by an expert in the social care organisation for adults with learning disabilities the author was based in prior to use.

Data collection methods, including the interview guide, quiz and vignettes were also pilot tested with carers and adults with learning disabilities prior to interviewing participants for the study. Appropriate modifications to process and format were made to aid accessibility.

Interviews took place informally in community settings which were familiar to participants and afforded some degree of privacy, including care homes, day centres, cafes, parks and over the telephone where appropriate. These were audiotaped and interview length ranged from twenty-four minutes to an hour and forty minutes, though most took 45 minutes.

Data was collected using an iterative approach. A subset of carers were interviewed first, and their interviews transcribed. Notes were taken in this process to inform some of the questions for adults with learning disabilities if appropriate (for example if they struggled with the concepts discussed and needed examples). A proportion of adults with learning disabilities were then interviewed and these transcribed, followed by the second subset of carers, and then finally a small number of people with learning disabilities to complete the sample.

The vignettes and pictorial aids were also used where appropriate to engage participants with learning disabilities. The former were adapted in interview to their own living circumstances. This aimed to engage them in more concrete examples of the constructs being discussed, consistent with Young & Chesson (2008) and to stimulate discussion and maintain privacy of participants and their carers. Follow up prompts were used where appropriate and participants could also have the assistance of a talking mat if needed to make decisions about what they felt was important from a limited number of options.

The interview guides and vignettes were used consistently in the first wave of interviews with carers and adults with learning disabilities as originally devised by the researcher. However, these were adapted and shortened during the second wave of interviews with seven participants following transcription and preliminary analysis of research findings. This was used to generate more targeted questions with participants to address data gaps and novel lines of enquiry. In the third and final wave of data collection the researcher only used the interview guide and vignettes where necessary to gain data on participants' conceptualisation of healthy eating, physical activity and in the case of carers, sedentary behaviour. The rest of the interview questions were guided by remaining gaps in the data and enquiries that had been generated during the research process described above.

## **5.9 Analysis**

The food and activity preferences of adults with learning disabilities were analysed for internal consistency using Cronbach's alpha in IBM SPSS (version 24).

The interview data was collected and analysed using NVIVO 11 software. Thematic analysis was carried out on the data. As a theory-based approach was used, it was grounded in a realist epistemological perspective and analysis was deductive; that is '*top down*' rather than

*'bottom up'*. This helped organise the data and make comparisons between participants' views in relation to the themes and sub-themes from social cognitive theory used to categorise and make sense of the data. Some additional findings from the data were also coded and grouped into additional themes inductively where appropriate. This applied if they were deemed to be relevant to the understanding that participants and their carers had around healthy eating, physical activity and sedentary behaviour, and their determinants in this population. Analysis followed the guide by Braun & Clarke (2006) in these circumstances. Two interviews were subsequently secondary-coded by an independent reviewer not involved in the research project using a coding framework to guide their process (Appendix C), representing approximately ten percent of the data. This consisted of one interview with a carer and another with an adult with learning disabilities. Coding discrepancies were resolved through discussion with the researcher.

## **Results**

### **6.1 Demographics**

Twenty-four participants took part in the interview study in total, though one adult with a learning disability withdrew after we had discussed healthy eating as they no longer wished to participate after we discussed this topic. The sample consisted of 12 adults with learning disabilities and 12 carers (see Tables 1 and 2 below). Most carers were white, relatively well educated, with significant experience in supporting adults with intellectual disabilities (median length of time of having provided support was 19.5 years). Most participants with learning disabilities had mild learning disabilities, half were ethnic minorities, and 8 had support from paid staff, though one also had help from family. Three others were supported by family, and one was fully independent without support. Overall fifty percent of participants were female and fifty percent male and ranged in age from their twenties to late sixties.

Table 1: Participant characteristics of carers

Participant name*	Wave	Ethnicity	Sex (F/M)	Age band (yrs)	Education	Role	Primary Carer (Y/N)	Length of experience
<b>Emily</b>	1	White British	F	31-40	Undergraduate	Deputy Manager	N	>5 years
<b>Nora</b>	1	White Irish	F	51-60	Undergraduate	Manager	N	>20 years
<b>Sarah</b>	1	Mixed Race	F	41-50	Undergraduate	Senior Support Worker	Y	>20 years
<b>Bob</b>	1	Black Caribbean	M	61-70	Post-graduate	Manager	N	35 years
<b>Joe</b>	2	White British	M	41-50	Post-16	Manager	N	3 years
<b>Kate</b>	2	White British	F	41-50	Post-16	Day Service Worker	Y	2 years
<b>Sandy</b>	2	White British	F	51-60	High School	Family	Y	20 years
<b>Dave</b>	2	White British	M	31-40	Post-graduate	Support Worker	Y	12 years
<b>Leanne</b>	3	White British	F	25-30	Post-graduate	Family and Co-ordinator	N	>25 years
<b>Karen</b>	3	White British	F	61-70	College	Family	Y	40 years
<b>Mike</b>	3	Black British	M	25-30	Undergraduate	Support Worker	Y	23 months
<b>Natalie</b>	3	White British	F	61-70	Post-graduate	Family	Y	19 years

Table 2: Participant characteristics of adults with learning disabilities

Participant name*	Wave	Ethnicity	Gender (W/M)	Age (yrs)	Level of LD	Primary source of support	Preferred communication method
<b>Jay</b>	1	Black Caribbean	M	NK	Mild	Support Worker	Verbal
<b>Sunil</b>	1	Asian British	M	NK	Mild	Support Worker	Verbal
<b>Matteo</b>	1	White European	M	53	Moderate	Support Worker	Verbal and gesture
<b>Dean</b>	1	White British	M	NK	Mild	Support Worker	Verbal
<b>Jordan</b>	1	Black African	M	37	Mild	Support Worker	Verbal

<b>Stan</b>	1	White British	M	52	Mild	Support Worker	Verbal
<b>Anne</b>	2	Black British	F	28	Mild	Support Worker	Verbal
<b>Peter</b>	2	White British	M	28	Moderate	Family	Verbal
<b>Kevin</b>	2	White British	M	23	Mild	Family	Verbal
<b>Abayomi</b>	3	Black British	F	43	Mild	Family	Verbal
<b>Claire</b>	3	White British	F	29	Mild	None	Verbal
<b>Aisha</b>	3	Mixed Race	F	20	Mild	Family and support worker	Verbal

\*Pseudonyms were used in place of participant names to maintain participant anonymity

## **6.2 Internal consistency on food and activity preferences amongst adults with learning disabilities**

The food and activity preferences of adults with learning disabilities showed high internal consistency (Cronbach's  $\alpha = 0.99$ ). Several participants consistently did not inform the researcher that they enjoyed healthy options presented to them, but unhealthier alternatives, which supported the premise of authenticity in later interview responses by participants. A couple of participants also showed differing levels of enjoyment of healthy food versus physical activity.

## **6.3 Knowledge about healthy eating**

### **Carers**

Carers generally demonstrated similar ideas about what constitutes a healthy diet. All mentioned the importance of eating fruit and vegetables. Several also mentioned the importance of also including proteins, complex carbohydrates and dairy in a varied and balanced diet.

*“Erm healthy eating for me is-is eating a balanced diet. Including erm fruit, vegetables, proteins, carbohydrates, all in er-all in er balance that compliments your body”* (Joe, Manager).

Some also mentioned having enough vitamins and minerals, fibre, and green vegetables being good for the body, as well as lean meats, though the depth of knowledge varied between participants. Several mentioned the importance of drinking enough water. One had very detailed knowledge about important components of a healthy diet.

*“Vegetables more than fruit, because fruit’s high in sugar. Erm grains that are naturally wholewheat erm rather than some others, like brown rice, rather than white rice. Erm lean proteins not fatty proteins, more on the white end of proteins like chicken and fish, rather than red meat like steak... looking at different types of fats, whether it’s saturated or unsaturated, poly-[unsaturated fats]”* (Kate, Day Service Worker).

They also agreed on what may be unhealthy, suggesting that foods high in fat, salt and sugar, or ‘junk food’, takeaways and ready meals being unhealthy, as well as for some, processed foods. One gleaned this from recent public health campaigns against high sugar intake in the media.

Participants also suggested healthy eating involved a person having regular meals and cooking food properly, suggesting improper cooking would result in loss of nutrients, though one also stated eating raw vegetables could be good for individuals. Three participants also raised the issue of meeting individual needs in healthy eating, as they felt it important to consider issues such as allergies and intolerances faced by particular clients:

*“Also you wanna be looking at whether there’s any dietary things or specific conditions...you might not be able to eat certain things and therefore you might have to exclude those from the diet cos they might make you ill”* (Emily, Deputy Manager).

Some paid carers, particularly managers, ascribed importance to catering to individual requirements from differing cultures though they emphasised need to ensure it was done

healthily. In this context they talked about having a culturally diverse staff team as an asset, as they may be able to cook dishes for clients with greater skill and authenticity.

Finally, several participants raised the need to consider health and safety issues when cooking. They were particularly conscious that adults with learning disabilities needed to be properly taught how to prepare, cook and store food. They could then have those meals outside of their support hours when convenient without expending too much time and effort.

### **Adults with learning disabilities**

All participants with learning disabilities were able to give examples of healthy and unhealthy foods, some by using pictorial aids. They all identified fruit and vegetables, salad and drinking water as healthful, and biscuits, crisps, chips, burgers, pizza and chocolate as unhealthy, as well as too much oil or salt in food. Some talked about particular dishes they cooked such as tomato soup, being healthy, and favourite foods, such as chicken korma being unhealthy. This was because the latter was a ready meal. Another participant did not demonstrate understanding that ready meals could be considered unhealthy, but appeared to confuse eating healthy food with taking appropriate health and safety precautions:

*(laughs) "You cook in five minutes... I can get this cooking it, I not eat er-er uncooked food"*  
(Matteo, Adult with Learning Disabilities).

This also related to the value participants put on being independent and able to demonstrate their competence to the researcher.

Concerns about health and safety nevertheless had some merit, as another participant talked about how she had almost burned herself whilst trying to cook without support and another attempt at cooking a meal had resulted in her son being hospitalised for food poisoning. Struggling to understand time was a key barrier to this person being able to cook well.

*"I thought I done everything right and then she just said to me you can leave it on for half an hour more and then I said I read it and that's what I thought-I did, so my son had to go to the*

*hospital and then luckily he was alright but I-I had a panic attack” (Abayomi, Adult with Learning Disabilities).*

A few participants talked about healthy cooking methods being important including grilling rather than frying food. One also spoke about substituting in healthier ingredients for making their favourite meal. Some participants talked about need for moderation and portion control when cooking and eating out. Participants seemed aware of where they could shop to buy healthy foods, all suggesting that they could purchase them at markets and stalls. Several participants understood eating takeaways could be unhealthy and were aware of numerous such local establishments. However, one talked about difficulties he had in ascertaining which options were healthy and unhealthy when going out to eat:

*“Erm, healthy er-they should put a sign of shop where healthy shop is” (Jordan, Adult with Learning Disabilities).*

Both participants with learning disabilities and carers identified the importance of providing accessible information so that people with learning disabilities could better understand how and why participating in health promoting behaviours is important for their wellbeing. This would also enable them to communicate their own preferences to carers.

#### **6.4 Knowledge about physical activity and sedentary behaviour**

Participants gave several examples of physical activity and where they could occur, with pictorial prompts where appropriate, primarily involving recreational sport. Only two carers defined physical activity using national guidelines. Both talked about physical movement that would raise heart rate above a normal range. They focussed on cardiovascular rather than muscle strengthening exercises though the latter could potentially be more accessible to users with impaired mobility. Nevertheless, most carers contextualised their definitions of physical activity for adults with learning disabilities by their needs and abilities, aiming for realism as a significant proportion of this group have additional physical impairments to consider.

*“I mean I guess any kind of movement, for half an hour at least, er any-you know at least half an hour walk a day or something like that...maybe a little bit of sport, jog...Erm yeah I guess it’s really different with people of different abilities” (Leanne, Family Carer).*

Another person stated:

*“Well I think even being in the kitchen, stretching, for some people, they might not do, they might be really sedentary, they might not do anything-So being in a kitchen, um, engaging in some kind of recipe, stretching, is some kind of physical activity for that person”* (Emily, Deputy Manager).

There was considerable overlap between definitions of physical activity and sedentary behaviour by carers. Only two defined sedentary behaviour accurately as activity involving sitting and lying down. However, others had not encountered the term, including one working in public health. This is not surprising perhaps and may reflect a lack of awareness in wider society.

## **6.5 Knowledge about the effects of increasing healthy eating, physical activity and sedentary behaviour on health**

### **Carers**

Carers tended to have greater knowledge about consequences of healthy eating and physical activity on physical and mental health. They outlined the benefits for physical wellbeing, daily functioning, weight management, disease prevention and longevity. Several talked about the positive impact of healthy eating and physical activity on mood, self-esteem and subjective wellbeing. They also described positive social effects such as potential to enhance inclusion and visibility in local communities.

### **Adults with learning disabilities**

All but one participant demonstrated that they knew that healthy eating and physical activity could be good for health. When it came to explaining why this was beneficial, understanding varied widely between participants. One participant said non-participation in healthy living could perhaps cause someone to collapse or have a seizure. Several, including this participant, linked healthy eating and physical activity to weight management. Alternatively, they suggested an unhealthy lifestyle may *‘put a strain on your body’* via overweight or obesity and cause heart problems or disease more generally. Their emphasis was on avoiding

these negative physical consequences of an unhealthy lifestyle, whereas a couple of others linked healthy eating and physical activity positively with keeping fit and being stronger. They also talked about the beneficial impact it could have on their mood and mental health, one using this to alleviate anxiety. Another talked about this in greater depth than the others:

*“It helps to boost up our levels because even food is good for mood, so it’s-it’s good for helping our mood swings and it’s good for depression, it’s good for anxiety, it’s good for stress levels, it’s good for all different types of things”* (Claire, Adult with Learning Disabilities).

Healthy living was particularly important to this participant and she described spending considerable time on the internet looking at healthy food information. There was a large gap in level of understanding this person demonstrated in comparison to some others, showing the heterogeneity of depth of knowledge, understanding and communication skills between participants.

## **7 Outcome expectancies**

Most participants had some positive outcome expectancies around healthy eating and physical activity, primarily driven by awareness of its’ benefits to physical and mental health. Several, particularly carers, were also interested in other positive outcomes when supporting adults with learning disabilities with health promotion, including socialising, improving skills and knowledge. This also included other outcomes which were at best, tangentially related to health. Several expressed concerns, however, about how to motivate the people they supported to engage with healthy eating, physical activity and reducing sedentary behaviour.

### **7.1 Immediate hedonic responses**

#### **Healthy and unhealthy food**

Most participants put emphasis on ‘*short-termism*’ when motivating engagement with food and activity. Difficulties stemmed from food being viewed as a key source of pleasure for some adults with learning disabilities. Indeed, one family carer did not want to engage with healthy eating as they believed that this meant ‘*no treats*’. This also caused ambivalence for

another paid carer as they believed it was perhaps the only pleasure some of them had real control over and access to, partly because they were known and familiar.

*“If you remind him that his doctor said that he shouldn’t have too much sugar, then he won’t do it...But-but he very much uses it to put-like his coping mechanisms and er-er when you think you know, how I’m taking away his coping mechanism...He hasn’t got anything else to do”* (Dave, Support Worker).

To some people then, healthy eating meant causing deprivation of enjoyment for people they supported. Several carers and one person with a learning disability described unhealthy eating as a coping mechanism for mental health issues, loneliness and boredom in absence of other options.

Another carer suggested, when asked for examples of unhealthy food, that these were *‘anything that tastes good really’*. Though when probed as to whether healthy food could also taste good she agreed and gave examples of how food could be prepared to be healthier and enjoyable:

*“Like you can use herbs and spices to cheer things up with, you know?”* (Sarah, Support Worker).

However, this suggests making healthier food tasty and pleasurable involves greater effort whereas unhealthy food is inherently pleasurable, hedonic and accessible. Another carer suggested flavour enhancers in unhealthy food played a key role in this. Several carers also emphasised need for healthy food needs to be enjoyable to motivate adults with learning disabilities to initiate healthy eating. Several carers also suggested flexibility was important when supporting adults with learning disabilities and giving people they supported the opportunity to eat unhealthy foods in moderation or as an occasional ‘treat’:

*“You don’t want to upset-to set somebody up to feel like they’re actually failing”* (Nora, Manager).

Thus, they placed importance on not putting clients under excessive pressure. Self-regulation of behaviour could be quite effortful and most carers felt that it would be important for adults

with learning disabilities to have some respite from this. They felt that enjoyment of food in general was also quite important for quality of life of those they supported and a key source of motivation to sustain healthy eating.

### **Physical activity**

Most participants, particularly carers, discussed the importance of making physical activity enjoyable to motivate engagement by adults with learning disabilities. However, some participants with learning disabilities suggested people should be supported to perform physical activity irrespective of this, closely linking this to weight concern.

### **7.2 Weight concern**

Weight concern was a key issue for several participants, carers and adults with learning disabilities alike. Two participants with learning disabilities talked about how they equated healthy eating with weight loss and positive body image, whereas unhealthy eating was linked with overweight, obesity and condemnation:

*“Losing the weight forever...So you can look good in your clothes when-when-if you are out and about or you’re going away-you don’t have to be ashamed of-of-of how you look...Cos that just what happen with a lot of people and even-even the young people-obesity”* (Jay, Adult with Learning Disabilities).

Conversely, overweight by eating unhealthily was associated with being ‘*ashamed of how you look*’ and negative criticism from themselves or others in the wider community. It seems that eating unhealthily also indicates a personal failure of control to these participants. This ties into wider cultural narratives about weight and attractiveness. It may also indicate the greater pressure adults with learning disabilities can feel to present an acceptable image to wider society as an already marginalised minority.

Some carers also demonstrated that they linked healthy eating with weight control. Sarah, particularly, described experiences of several clients with overweight and obesity that were unable to change to healthier eating patterns, though she conflated their intentions and behaviour. The only person with a learning disability she had noted that consistently had a

healthy weight was a woman who chose healthy options habitually when presented with options in their care home. This was because she had been encouraged to do so to maintain attractiveness by her family over a long period of time.

One participant with a learning disability also discussed conflicting advice they had received around eating healthily and consuming unhealthy food. This appeared to result in confusion about how to proceed:

*“Because if you drink-if you eat junk food they say oh no it’s not good for you, but then if you eat healthy they might think you’re trying to lose weight or trying to become an anorexic person, so I don’t really know how to win with certain people...To be honest”* (Aisha, Adult with Learning Disabilities).

For this participant, it was difficult to know at times whether to engage with healthy eating due to conflicting advice by a family member and friends about her eating habits. She was quite slender and seemed concerned about possibility of losing weight and others’ perception that she would develop an eating disorder. However, she had also been told that eating and drinking unhealthily would result in damage to her teeth, often by the same peers and family. This resulted in considerable frustration for this participant and demonstrates how strong associations between diet and weight concern were for several people in this study. Weight concern was also important for participants in both groups to encourage physical activity, but to a much lesser extent.

### **7.3 Health concerns**

Some adults with learning disabilities also engaged with healthy eating and physical activity when concerns were raised about their health and at times this overlapped with weight concern. One participant described the negative impact of obesity on their health and another participant identified having too many takeaways as a motivator to try to eat more healthily:

*“Yeah the takeaways are what got me into trouble isn’t it?... Eating too much of them, and it’s putting pressure on the heart as well isn’t it?”* (Sunil, Adult with Learning Disabilities).

This individual was also trying to lose weight, but his initial motivation to eat more healthily and do exercise was due to what seemed to be a health scare. He seemed to realise that his eating habits had personal negative consequences for his health so decided to change his behaviour. It also appeared to be very important to him as he was quite detailed about behavioural management strategies he used.

Two carers, one support worker and one family carer, talked about how, in their experience, people only generally attempted to change their behaviour when they were told they needed to, to avoid illness, for example:

*“The usual considerations have been for health reasons because their doctors told them to... Or a carer has told them, that they need to lose weight or they need to be more, avoid diabetes and that sort of thing”* (Sarah, Support Worker).

A key approach to motivate adults with learning disabilities seems to be carer communication about the illness consequences of a poor diet and low levels of physical activity. Having a ‘health scare’ then brought urgency to the situation. This links with what participants with learning disabilities knew about healthy living and avoiding health problems as discussed earlier. Another carer expressed concern about use of negative rhetoric around healthy living, encouraging sharing positive information about benefits of healthy eating and physical activity instead. This included the role of vitamins and minerals in maintaining a healthy body. One adult with a learning disability also expressed concern that physical activity was causing him lung problems as he would begin exercises being cold, so did not understand that participating in physical activity would involve warming up during exercise. This indicated a sense of hypervigilance about his health and reflected the close scrutiny he appeared to be under by his carers. This will be discussed further when considering the impact of social support on uptake of healthy eating, physical activity and reducing sedentary behaviour.

#### **7.4 Purpose**

For some people improving healthy living taking part in activities that serve another primary purpose appeared to be important. In some cases this was for pleasure or enjoyment, but for others it involved developing skills and opportunities to meet their aspirations, an alternative to using other forms of transport or to do an activity one desired.

## **Employment and responsibility**

Participants with learning disabilities often ascribed importance to learning new skills and becoming more independent. This was clearly something they valued highly, partly for potential opportunities this created for them. Jordan, an adult with a learning disability, talked about how gaining cooking skills could lead a person to gain employment:

*“Yeah probably they can get a job. Their own restaurant maybe”* (Jordan, Adult with Learning Disabilities).

He talked at length about practicalities of this and it strongly suggested he had thought about this for some time. A family carer also talked about how a manual job could be key to engaging her son with learning disabilities and autism with physical activity as it was something he was otherwise reluctant to do:

*“He’d-he’d be much more likely to do that, than he would-I mean that’s really would be the answer I think, to-to have a manual job, where you’re doing physical activity because you’re working, he can see the point in that”* (Natalie, Family Carer).

Part of the issue then is that sometimes adults with learning disabilities struggle to understand the reasons for eating healthily and being active, unless they learn experientially. Another participant, manager of a gardening centre, also talked about how part of his role was to educate adults with learning disabilities to improve their gardening skills to gain employment opportunities within the borough. He also spoke about, how for one individual with more severe learning disabilities that there was one particular task that he would engage with as he understood what to do and its’ purpose. This same individual do so with other tasks as they lacked meaning to him or his participation seemed irrelevant. This participant stated that at times his carers would also come to him to check when the next opportunity to do this job occurred as they had noticed it had a positive impact on their clients’ mood and behaviour.

One of the participants with a learning disability was passionate about gardening. She suggested it would be helpful to teach adults with learning disabilities to grow their own fruit and vegetables so they could gain a sense of achievement from the products of their labour. A

manager shared this view but cautioned against giving too much information at once to some adults with learning disabilities as they may find this overwhelming, so emphasised gradually increasing knowledge. Another adult with mild learning disabilities talked about her desire to gain cooking skills to entertain friends. A third talked about walking instead of using public transport to travel rather than doing so for inherent enjoyment. Finally, a family carer talked about engaging her son in active tasks at home to engage him with responsibilities and how this ensured that he was not too sedentary.

## **8 Self-efficacy**

Carers tended to engage with the concept of self-efficacy much more than participants with learning disabilities. This was primarily due to its' complexity. However, it was discussed in the form of self-confidence and self-esteem as these are more familiar lay concepts rather than self-efficacy per se. Key influences of self-efficacy for adults with learning disabilities were gaining knowledge and skills of how to live healthily, recognition of their achievements and role modelling of behaviour.

### **Self-efficacy for adults with learning disabilities**

#### **8.1 Knowledge, skills and recognition**

Self-efficacy developed amongst adults with learning disabilities when they were given opportunities to develop their knowledge and skills on how they could eat more healthily and increase activity, rather than focussing on why it was important. For some, increases in physical activity or healthy eating were incidental, whilst they gained mastery in skills that increased their technical competence in, for instance, cooking or gardening. This was particularly true when gaining additional responsibility, gains in status amongst peers and moving towards their aspirations.

*“I work with many individuals but if I can just think of one or two of the higher-higher functioning ones-they then-they then erm look for further work and ask about that but then they would also take themselves off and do work of their own-using their own initiative...And so include other people within that task that they're doing... become a team leader...So*

*they're empowering themselves to make a decision that they would then, nine times out of ten get praised for"* (Joe, Manager).

Volunteers with learning disabilities were in a garden centre that encouraged them to develop their skills and use their initiative, within requirements of the business. Some, particularly those with milder learning disabilities were then able to take on tasks more autonomously and lead their peers in carrying these out, thus also acting as role models. A family carer whose son worked in the centre noted that this had a positive impact on his confidence and ability to socialise with others:

*"Brings him out of his shell...Cos he's very shy and...Doesn't talk to people... It does make a big difference...He's more outgoing, he'll sit and chat to you...It-it makes it much better"* (Sandy, Family Carer).

The effect of recognition and praise on adults with learning disabilities had a particularly strong impact on their self-efficacy and engagement according to most participants. One manager talked about the importance of regular '*checking, reassurance, praise*' and explained that his volunteers would seek out the latter after they had finished tasks, though he was careful to do so on basis of merit.

Self-recognition of achievements also seemed to be important for self-efficacy of adults with learning disabilities as this could improve their sense of mastery as observed by carers and some adults with learning disabilities alike:

*"There is a pride in knowing it...There's a pride and there's a showing off...you-you-you can be really surprised, you know, and he'll say things like this doesn't work like this, you do it this way, and you think, do you? And you do it and he says, told ya...And you can see he has-he has this quirky smile you know...A kind of a lip twist as if to say haha got one over ya"* (Karen, Family Carer).

This recognition came from being able to share knowledge with another person. In this case they were teaching someone able-bodied and without a learning disability. As adults with learning disabilities are expected to learn from their carers rather than teach them skills, doing so may have helped reverse power dynamics temporarily, something clearly enjoyable

for the person they supported. Additionally, a participant with a learning disability described being responsible for themselves as a sign of maturity and independence:

*“No I think I don’t really need people like that. If I can go myself, I can go myself. I’m being con...It means I’m being confident for myself...I can do things by myself....Like I’m-I’m fifty three years of age now...I don’t need much people supporting me to do that. I do it myself”* (Dean, Adult with Learning Disabilities).

Being perceived as a role model for other people could also increase recognition and self-efficacy for adults with learning disabilities and another described this as a source of inspiration.

## **8.2 Role modelling**

Observing other role models could have positive and negative influence on self-efficacy of people with learning disabilities. Their main role models were peers, carers and celebrities. Role modelling was potentially particularly useful to encourage tasting novel foods, something adults with learning disabilities sometimes struggled with due to food sensitivities and rigid, habitual behaviour. Indeed, for one carer with a family member that had autism, intervention was important as their diet was originally very restricted. Without this, they would have difficulties adapting to wider culture in adulthood as their choices might not always be available.

*“I don’t want him to be twenty-five and living on chicken nuggets, bread rolls and raw carrots”* (Natalie, Family Carer).

For this person a key break through was when a sibling acted as a peer role model and was able to persuade them to add milk to cereal. For this carer this was a huge break through as they would not mix dry and wet food and it helped lead to other changes in their diet.

Another carer pointed out:

*“I think we (laughs)-you always trust your friends...no matter who you are-So if your friends are trying it first you’re more likely, to give it a little go”* (Kate, Day Service Worker).

A manager also suggested that future intervention efforts could involve engaging a friend in taste testing to introduce new foods to clients, albeit it also needed to be palatable and tasty to both to have the intended effect.

Carers could also act as role models for trying new foods and activities and the same participant stated that support staff did not always realise how powerful they were in this regard. He stated that clients watch staff and sometimes want to emulate them, so it was important that staff were mindful of this and presented positively about healthy eating whilst working with their clients as part of their professional role. Close working relationships between staff and particular clients could also increase their personal impact. However, a participant with a learning disability described how this could be detrimental, leading some to initiate unhealthy habits to feel included and connected with staff on a more equal footing.

*“They want to join in and feel like they are a carer or a support worker, and once you feel comfortable with joining in with them and make them feel like the carer and the support worker are-is like a friend of them because of the instance of what they’re doing”* (Claire, Adult with Learning Disabilities).

However, a carer recounted how she had tried to role model healthy eating for a person she befriended with a learning disability, yet this made no impact on their choice to have an unhealthy meal in McDonald’s every time they met:

*“Now every time we have a McDonald’s together, I always, and I mean this, I always make sure I have the grilled chicken salad...And a bag of fruit...But no, she has to have Big Mac...Large fries...And a large er milkshake”* (Sarah, Support Worker).

This shows that role modelling by carers does not always impact behaviour, particularly when involving ingrained habits and some behaviours were repeated by the carer to persuade them to eat more healthily. It was unclear if this person saw it as their weekly treat. It might then impact their behaviour if they spent more time together or if the carer used a different strategy, such as sharing a new food with the individual. Nevertheless, this carer acted as role model for several other adults with learning disabilities through competing to see who could lose more weight than she could, as she felt it was also a concern for herself. This garnered considerable interest amongst service users, some participating in the challenge for six

months and maintaining efforts beyond this, though the challenge fizzled out. This nevertheless showed how effective role modelling and treating clients as equals facing the same challenge could be when initiating behaviour change.

Celebrities were also considered potentially inspiring role models because of their achievements and status in society in the context of physical activity and body image. A positive example was provided by Kate:

*“The whole point of something like the Paralympics was about inspiring people...of different-differing abilities, you know... we play a sport... called boccia, and we discussed all the...Paralympians that had done that, and we got the pictures up on the wall”* (Kate, Day Service Worker).

Paralympians were considered a very real and tangible role models for adults with learning disabilities as they were relatable. A family carer also described how her son was very enthusiastic about the Olympics and Paralympics and followed them avidly on a daily basis. He was also a runner, and treated Usain Bolt as a friend, one that he knew *‘intimately’*. Discussing athletics was also a good way to connect with this individual. Conversely a lack of role models with learning disabilities in cooking programmes was lamented by one carer and an adult with learning disabilities. The latter suggested making a cooking video featuring adults with learning disabilities and sending this to a cooking programme, indicating some may aim to see themselves represented in mainstream media.

Celebrity role models, particularly in pop culture, were also seen as negative role models if their aim was to market products and sell a false body ideal. One participant noted these advertisements sometimes promised quick and easy toning of the body which may be unrealistic for most people. Products could also be costly and most adults with learning disabilities in this study did not have much disposable income.

Some participants also felt celebrities made fickle and intangible role models, stating a realistic role model, such as a peer with learning disabilities may have more immediate impact. Some participants with learning disabilities did not display enthusiasm for celebrities, either, as role models. However, a carer also cautioned that if a role model experienced a *‘fall*

*from grace*’ the effect on recipients could be much greater if they were relatable, such as a peer:

*“People will emulate that and if they see you fall, it could create a great disappointment in them.... Because you for some reason identify with that person...there is a real person you do get to see them and you will get to interact with them and if they fall from grace, then to me, that could potentially have a more significant impact than someone on television”* (Bob, Manager).

This could also put role models under pressure, exacerbating the risk that they do not live up to expectations, if these are not managed with people they aim to help.

### **Self-efficacy for carers**

Carers generally said that the main influence on their self-efficacy involved having knowledge about healthy eating and physical activity and how to support adults with learning disabilities with this. This included ability to deal effectively with challenging behaviour and collaborate with other professionals and carers.

### **8.3 Cooking**

Paid carers identified having opportunities to develop their own cooking skills and experience as a key factor for carers to be able to support clients effectively. Most paid carers developed these skills informally at home rather than at work and participants recognised the utility of this. Other support workers also pointed out that there was a lack of formal training for staff to develop their cooking skills, noting that many paid carers go into social care with very little experience in this area:

*“I think education around nutrition, would help...And cooking as well, because some people can’t cook for love nor money, let’s face it... a lot of people coming into working with people with LD with not masses of experience most of the time ...and I think also that, when you look at the training that’s available to staff...It doesn’t include nutrition”* (Kate, Day Service Worker).

A participant with a learning disability also observed this regarding his own carers:

*“They’re about nineteen-twenty you know them people can’t, really... probably their mum or dad must cook depending on... Older brother or sister, probably cook for them innit?”* (Stan, Adult with Learning Disabilities).

Participants did not discuss informal cooking learning in the work context either, suggesting this was not routine practice. Conversely having good cooking skills seemed to be the norm for family carers, coupled with detailed knowledge about dietary preferences and needs of people they cared for, most likely due to their longstanding responsibilities in their roles. Even a family carer that not want to engage in healthy eating stated it would not be any more burdensome to cook healthily rather than unhealthily at home.

#### **8.4 Challenging behaviour**

Another key factor in determining carer self-efficacy was anticipation of and ability to deal with challenging behaviour as it arose. This could be related to defensiveness or anxiety from people with learning disabilities when dealing with uncertainty, including when carers engage them with behaviour change.

*“Sometimes you can get behaviour that challenges, and that person’s’ going what you gonna do about this?... Are you gonna be able to make me feel safe, are you gonna be able to deal with me, that’s what they’re doing”* (Emily, Deputy Manager).

As mentioned in the excerpt above people with learning disabilities sometimes show challenging behaviour to test a carer’s’ reaction. Highly motivated and self-efficacious staff supporting that service user would be better equipped to cope with this behaviour. Their knowledge and understanding of the person and experience of how a service operates also influences ability to respond in an appropriate manner. A family carer also noted that anticipated challenging behaviour sometimes meant that families did not engage with trying to promote healthier behaviour with loved ones who had learning disabilities and autism:

*“I can speak from my own experience and other children that I’ve seen grow up alongside my son and erm very very restricted food choices...which is very very difficult to unpick and to-*

*and to manage ... a lot of parents...won't try to introduce new foods, erm in order to just keep the child happy, so they can go all the way into adulthood with a very... restricted diet"* (Natalie, Family Carer).

The challenges faced by families in trying to support a person with learning disabilities to eat healthily and increase physical activity should not be underestimated. This, coupled with concerns about challenging behaviour, may have felt unmanageable to some families, sometimes resulting in them not being addressed for significant periods of time.

## **9 Proxy efficacy**

Adults with learning disabilities often relied on carers with decision making in many different areas of their lives, due to difficulties some had in understanding which foods were considered healthy and unhealthy. They also depended upon carers for other skills needed to manage this on a regular basis, including paying for groceries, meal planning and researching and attending appropriate leisure activities in the local area. For these reasons, having a good relationship with carers was as important for adults with learning disabilities as for carers, if not more so. Key attributes to build and maintain this relationship appeared to be trust, familiarity and consistency in support:

*"Yeah I mean he-he-he doesn't trust many people because he's obviously-he's autistic he doesn't interact that well with many people and his natural style is not to. But he trusts me...to do the right thing for him so er that's been hugely important because er he knows I'd never do anything [to] hurt him."* (Natalie, Family Carer)

For this individual with autism and difficulties trusting others, knowing that his parent would always aim to help him and not harm him was crucial to building that trusting relationship between them. This helped enable her to gradually support him to have a more varied diet. It was also important for paid carers as a close working relationship could potentially be leveraged to introduce new foods and activities to clients they might not have otherwise considered. This could be achieved by modelling healthier behaviour and having conversations about healthy eating and exercise to arouse curiosity and interest via good communication. However, another participant felt it was more difficult with adults with mild learning disabilities living in social care:

*“Especially with mild learning disability... you get a lot of confident, you get a lot of nah I’m not doing it, nah, you know... And they’re the stuff I’m supposed to do, what I wanna do really, because I don’t want this person supporting me, so sometimes choices are made, through behaviour”* (Emily, Deputy Manager).

For adults with learning disabilities, at times, challenging behaviour enabled protest against support they had been offered and this could apply to health behaviours they wanted to engage with. This happened when staff were unfamiliar, did not appear to know how to cope with challenging behaviour or there was inconsistency in staff support, including use of agency workers in services. Alternatively, as a participant with learning disabilities stated, a client may not have much choice about whether they trusted in a carers’ skills:

*“Well they’re saying they are but you-I have to trust them because they might think oh yeah you’re being rude about that person...you can’t start giving comments saying...But some I know can’t cook and then when I pointed that out she said oh yes well I can”* (Stan, Adult with Learning Disabilities).

It is clear from the above that carers still have greater power in the caring relationship. If the person they support challenges them this may lead to conflict and personal affront by a carer so trusting them may become necessity to avoid negative consequences for their support.

Emotional dependence is another issue to consider when carers have a close relationship with people they support. This is something paid carers especially had to consider because as one participant stated, sometimes they are in *‘loco parentis’*. One paid carer talked about importance of teaching service users skills that they could use independently to prevent them from becoming over-reliant on a particular member of staff. Another support worker mentioned this was a barrier when attempting to engage some clients with health promoting behaviours. Several colleagues had worked in that service for many years and were much more able to engage them with this than newer staff:

*“Erm I would say it’s the length of time they’ve known em so, Fir’s like... in Fir you’ve got a lot of staff that have been there for twenty years. So they’ve grown up with them really...So they can-they can motivate them to do much more than some newer staff I think, yeah, yeah”* (Dave, Support Worker).

This was problematic as service users seemed to have become unresponsive to newer staff and quite rigid about whom they could trust. This may have factored into greater prevalence of unhealthy eating, lack of physical activity and greater sedentary behaviour by clients living in this service. Newer staff also often lone worked with service users in this context with little opportunity to shadow more experienced colleagues. This meant clients did not have many opportunities to see them collaborating as a team and build trust with newer colleagues. Dependence was also a potential problem for another adult with a learning disability who said that although he could cook, he relied on his parent to do it all for him. Clearly, he found this easier and preferable though he may not have understood long-term consequences when his parent was no longer be able to do this. Another parental carer of an adult with learning disabilities also explained that did all chores for her son although she knew it might not eventually help him:

*“Sometimes I think he should be more independent...But half of that’s my fault anyway...See I think he could do a lot more but I do everything for him...I think it’s just a mums thing isn’t it” (laughs) (Sandy, Family Carer).*

She saw this as part of her role as a mother that she had been socialised to follow. This seemed to be ingrained and her way of showing him care and attention but it maintained his reliance on her for support.

## **10 Social support**

Sources of support for adults with learning disabilities involved carers and peers, and for those receiving paid support, care managers and social workers. They tended to rely more on carers for practical and emotional support, and unsurprisingly, carers had significant influence on their daily lives. Peers could also have considerable influence, but this tended to be emotional rather than practical.

### **Carers**

Most adults with learning disabilities struggled to describe what they felt was desirable social support from a carer. This may have been partly due to difficulties with questions, but also possibly because they did not want to criticise their current carers.

## 10.1 Carer self-efficacy and manner

Carers identified importance of displaying confidence and knowledgeability about healthy eating and physical activity for persuading and motivating adults with learning disabilities to engage with health promoting behaviour. A support worker also suggested using a personable approach to engage service users was also important and disposition played a role in this:

*“I think having that confidence in the first place isn’t it? And just being an outgoing, cheerful disposition...Approaching-approaching things in a friendly manner rather than a dictatory, bossy way or, you know”* (Sarah, Support Worker).

This involved expressing their interest in the persons’ welfare, patience, humour and compassion. Abayomi, an adult with a learning disability, described how much a carer’s’ approach mattered to her:

*“Someone who can make a joke out of themselves, someone who can just have a laugh... like I think that you’re a patient person and I feel like I’m interviewing you...a lot of people, like my carers, they don’t sit and listen, you know?”* (Abayomi, Adult with Learning Disabilities).

Abayomi clearly indicated she wanted to feel valued, preferably as an equal. This contrasted with how she saw her own staff who clearly frustrated her. Another participant with learning disabilities also talked about need for carers to be *‘polite’* and *‘look after’* their clients.

## 10.2 Carer motivation

Some paid carers felt that some staff were not motivated to support clients to eat more healthily and be more physically active. This may be because they did not see it as a priority for themselves although variation in this regard could also be inevitable, as one participant noted. Carers also sometimes prioritised more tangible activities and outcomes such as appointments or medication. Using a reserved and distant manner was perceived as a more significant issue by some:

*“Sometimes I think if you’re too professional...And distant, putting people in boxes...so if say it’s a [healthy eating] programme that, I don’t know, the NHS are funding with some nurse...*

*I think sometimes that can go against you, because although it is important, it's too establishmenty... sometimes people can kick back on that as well” (Emily, Deputy Manager).*

Being too formal or promoting health using a clinical approach was viewed as problematic for providing effective support due to disenfranchisement of some service users. This could be particularly so if professionals appeared to be going through the motions rather than addressing healthier eating out of genuine desire to help. Conversely a programme with flexibility and responsiveness to individual needs in a relaxed or informal environment, alongside a holistic view of clients as complex individuals, would be more likely to succeed.

### **10.3 Values and choice**

One participant explained that to counteract the issue discussed above, values-based recruitment was being used at his organisation aiming to recruit those motivated to provide the best support they could to clients. This could be potentially problematic, however, when considering the balance between providing support to clients to lead healthier lives and respecting their right of choice, and carers had very differing views about this. For example:

*“I'd say it's really difficult because I think people maybe try ... to kind of maybe...just erm make people aware of healthy eating but at the same time no one's-no one is in a position to force someone's hand in eating healthily” (Leanne, Family Carer).*

Whereas another stated:

*“If somebody is clearly making an unwise choice that's gonna be detrimental to their health then I think they have a duty of care to that person if not professionally certainly morally to actually do something to encourage them as much as possible...just to say oh that's their choice and that's the end of it...that's unacceptable” (Bob, Manager).*

Whereas another carer felt that adults with learning disabilities should not necessarily have choice in this matter as they could not be relied upon to make healthier choices:

*“I think-I think generally speaking with-with the majority of people with learning diff-diff-disabilities...Is they need to be controlled. So it's not a case of necessarily what they want to*

*eat...It's what they need to eat, and trying to get round, the kind of things, that are out there, i.e. McDonalds, Kentucky Fried Chicken which we all like, it's gotta be said" (laughs)*  
(Karen, Family Carer).

From these excerpts it could be inferred that allowing adults with learning disabilities to make their own choices meant that they would make unhealthy choices. This may be due to hedonic impulses, lack of understanding of negative consequences of actions, or because their choices may be more variable than what carers would choose for them if they are in control. There is also a difference in the roles of paid and family carers as the latter could exercise greater control over their loved ones, whereas paid carers are obliged to respect the choices of people they support and not overly restrictive. These were generally perceived to be differing relationships, though a family carer may not necessarily feel able to coerce the person to make healthier choices. Rather, education and encouragement were perceived as key to enable engagement with these areas.

#### **10.4 Person centred approach**

Participants with learning disabilities and carers also emphasised a person centred, tailored and creative approach to engage users with specific behaviours. A carer that had tried to engage someone with healthy eating by role modelling without success adapted to this situation by focussing on a different behaviour:

*"You know going-going out and doing-having new experiences, or even just doing experiences of things that they enjoy...I mean I think about the lady that I befriend likes eating McDonald's junk food all the time, I mean I mean you give her choices and she always chooses that but you try and combat it by doing a lot of walking" (Sarah, Support Worker).*

This strategy also worked for another paid carer supporting clients when eating out in local areas.

Several participants also talked about importance of helping adults with learning disabilities to gradually change behaviour, giving them time to adjust and trust in the process. This was particularly important for clients with rigid behaviours including those with autism and challenging behaviour. This was also implicitly important when participants were gaining

knowledge and manual skills to develop participants' ability at their own pace, particularly if they were concerned about harming themselves, such as when learning to cook. One paid carer also talked about importance of having close healthier substitutions for unhealthy foods when introducing something novel to a client as familiarity was important, including having sweet potatoes instead of potato fries.

Another participant mentioned necessity of not overestimating abilities of adults with mild learning disabilities because they live independently. This could lead to frustration for that client and challenging behaviour alongside negative emotional and practical consequences for themselves and staff:

*“It’s also about picking up on things, if someone can feel under pressure...and if they can’t do it and they might have been under pressure then they might start crying...They might make an allegation against you”* (Emily, Deputy Manager).

Even if cleared of misconduct, the stress associated with being suspended could be discouraging for staff to engage people with learning disabilities in future with developing their cooking skills. Carers can be under pressure to tread a fine line between supporting an adult with a learning disability to strengthen these and managing their expectations, adding complexity and nuance to their role in supporting adults with mild-moderate learning disabilities.

### **10.5 Clear behavioural boundaries and consistent support**

Having clear and consistent boundaries were crucial according to paid carers experienced at facing challenging behaviour. Several stated this could help adults with learning disabilities to have a clear idea of carers' expectations. This involved separating personal and professional involvement, being assertive and helping them feel safe. It also involved persevering with difficult behaviour:

*“I saw people pandering to her every whim. And she played them, totally... so I changed tack, and I became very strict, not in a bad way, just assertive...Boundaried. And at first she was quite shocked, but I kept it up, and in the end, our relationship flourished because of it”* (Kate, Day Service Worker).

Another participant talked about being firm where necessary so people he supported understood what behaviour was acceptable and what was not. However, he also talked about using the ‘*carrot approach*’:

*“Nobody really likes to be told off ...it’s much more constructive to be erm more creative with them... show them the-the reason we’re doing it...And the bigger picture, which-which is my first approach...It’s actually engaging them with the erm job from start to finish, it-it’s showing them the finished product, erm and... rewarding them for the part they’re playing within-within that task”* (Joe, Manager).

For Joe, rewarding a client with recognition and inculcating a sense of being part of a bigger process was a positive way of dealing with challenging behaviour. This helped improve volunteers’ sense of self-efficacy and outcome expectancies, including bringing sense of purpose to their work. It also may have distracted them from their behaviour.

Some carers also saw consistency in routine as very important. One carer viewed this as even more important than consistency in whom provided support. However, another saw familiarity in staff coming to work with clients as more important to strengthen their knowledge and ability to meet clients’ needs. A manager also talked about consistency in keeping discussions about supporting their clients with healthy eating ‘*live*’, enabling clients with learning disabilities to contribute their suggestions into meal planning. This contrasted with another carer’s’ account where staff bought groceries for their service users based on ‘knowing’ their preferences from having worked with them for many years. This was often without input from service users themselves. The latter service found it difficult to engage their clients with healthy eating and this may have been one of the issues contributing to this.

## **10.6 Collaboration**

Having a collaborative approach with adults with learning disabilities and being perceived to coordinate well with other key figures in that person’s’ life was important to several participants. This could help adults with learning disabilities feel safe and help aid consistency in support. It also prevented clients from becoming too attached and emotionally dependent on one carer. Collaborating also meant staff members listening to each others’ input according to another manager. The emphasis on everyone having opportunity to

contribute their input indicates importance of inclusivity and shared ownership of decision making regarding supporting adults with learning disabilities to be active. Another paid carer took this one step further in respect of healthy eating and suggested having shared meals by staff and service users:

*“I think if there was something like one day a week, we all have a communal lunch, and we all brought one thing in, so it’s not just the service users doing it, the staff are included as well...Erm then everybody’s got that healthy lunch and everyone’s contributed...you can discuss what you’re eating as you’re eating...there’s no them and us anything going on”*  
(Kate, Day Service Worker).

This was an opportunity to involve clients in healthy eating in a relaxed and informal way with everyone invested in making this dish as they would contribute to it. They also argued it could take pressure off individuals by doing this as a group rather than individually as long as those who opted out were not placed under pressure. Another participant, with a learning disability, mentioned a previous successful peer learning initiative where adults with learning disabilities spent time together cooking and eating out. She was quite enthusiastic about this creating a safe environment for adults with learning disabilities to experiment with novel foods, excitement and sense of occasion. This could also reduce engagement in comfort eating and sedentary behaviour, by reducing isolation and boredom of participants.

However, there were caveats to sharing food in this way raised by other carers. Adults with learning disabilities could have very different habits and levels of rigidity and defensiveness about trying new foods. They could also have additional food sensitivities associated with their sensory needs, or other issues such as an inability to chew food due to poor dental health. One participant was able to offer her service users another option if they did not want to eat from the menu. This was successful and did not put them under undue pressure, providing needed flexibility.

Participants also talked about difficulties paid staff and family carers had in collaborating with each other when there were disagreements. This was mainly raised by paid carers, but it presented difficulties for family carers and became stressful for adults with learning disabilities themselves. Five out of eight paid carers discussed difficulties of collaborating with families because their roles and relationships with clients differed from that of families.

Notwithstanding this, one paid carer talked about how families of clients were very receptive to being shown how support loved ones when staff had visited family homes of their service users. This was after they had explained outcomes of such support in aiding them to maintain long term independence by helping clients maintain their mobility and skills. Another participant suggested using a non-confrontational approach detailing positive outcomes of intervening when first working with families to support their clients to eat healthily:

*“It’s about looking, again, at the benefits you’re looking for, what-what are the outcomes you’re looking for? Erm, so you need to be able to explain to them the benefits of healthy eating...And say I know you’ve done this like that for years but have you considered this and these are the benefits?”* (Bob, Manager).

Another paid carer suggested including families in a general health promotion intervention with adults with learning disabilities, rather than merely those considered to have a ‘*weight problem*’. They stated this would incur less defensiveness and be ‘*more welcomed*’ by families. A family carer also suggested use of positive case studies as this could be persuasive and encouraging.

Family carers also expressed frustration at the lack of support they sometimes had with certain things they saw as important from paid carers and other sources of support more generally:

*“I going to go back to the food diary actually because sometimes to parents that’s all they have sometimes to see what people are eating...Sometimes people forget what they’ve eaten, you know conveniently, and... if... you need to keep a food diary it’s probably for medical reasons so I kind of would like to see people kind of like keep it updated”* (Leanne, Family Carer).

Families can feel helpless and isolated in their attempts to support an adult with a learning disability from afar because they might not be involved in their everyday lives. This carer described becoming very reliant on the, at times, little information they received and they may not always understand dilemmas from staffs’ perspective. However, as this participant subsequently pointed out carers may be reluctant to share information to maintain clients right to self-determination. In some circumstance’s clients may decline them permission to do

so if they have mental capacity to make this decision. Carers may be able to negotiate this by persuading their client to share more of their lives with their families if they share a good relationship, but this is not guaranteed.

Another family carer talked about difficulties in engaging the rest of her family in supporting her son to vary his diet as a child, particularly her parents. Family dynamics must be considered when devising health promotion programmes for adults with learning disabilities living with families, as they would for any other person living in this context.

## **Peers**

Positive support from peers came from acceptance and mutual support. Dean, for example, talked about how he and his flatmates would take turns cooking for each other during the week with support from staff. For Abayomi this was key to her participating in activities such as sport:

*“I said well you guys are using two hands...I’m only using one. That’s not fair, why don’t we all use just one hand to catch the ball... So I got everybody... if I was somewhere else, with people I don’t know and I did that, I know they would probably laugh at me, but because I was with my friends, I felt confident”* (Abayomi, Adult with Learning Disabilities).

Likewise, a paid carer described how clients in his service often spending time together going on walks and playing badminton together, though they also balanced this with doing activities alone to get some personal space when needed. However, most peer support was characterised as negative, particularly by carers. One factor was peer pressure, particularly around unhealthy eating, including having takeaways and restaurant meals. One family carer raised the issue of machismo when a group of adults with learning disabilities she volunteered with socialised regularly at buffets together:

*“Yeah I think it’s to do with the people I hang out, I volunteer with...And they have this big thing about going to carveries and all you can eat buffets... okay it becomes a bit of a macho thing, I mean it is a macho thing anyway of how much can you eat”* (Leanne, Family Carer).

This participant suggested having a regular social event was important but redirecting it could

be complex as it involves moving away from instant gratification and a change of eating culture. They suggested having a healthy meal in a restaurant may not necessarily have been enough to interest these participants. A paid carer suggested people with learning disabilities may be more likely to engage in unhealthy eating even if they did not want to, to be accepted. Another suggested this may be more prevalent amongst youth with learning disabilities, as in wider society. They argued this could be exacerbated by focus on immediate hedonic outcomes for people with learning disabilities because they could struggle to understand long term consequences of their behaviour. Certainly, for one participant with learning disabilities, going out to eat *'junk food'* certainly seemed to be influenced by her peers as they did it together.

Peer influences could also take a darker turn and another adult with learning disabilities spoke about some people who would spend time with others who were unscrupulous:

*“And other people, do, you know, hang around with wrong people...Doing wrong things...And then they get in trouble”* (Jordan, Adult with Learning Disabilities).

This could have clear negative consequences for that person and others. A manager was also concerned about this when encouraging clients to go out walking and participating in community life. He felt that peers could take advantage of vulnerabilities of adults with learning disabilities and potentially involve them in crime. To balance this perceived conflict, they described informally *'vetting'* associates, encouraging service users to introduce their friends to facilitate monitoring. However, this could be difficult for those with greater autonomy as they may choose to meet those friends away from home and carers may not be aware of this.

## **11 Opportunities and Resources**

### **11.1 Support availability**

Most participants identified resource constraints in support provision for adults with mild-moderate learning disabilities as a significant barrier to healthy eating and participation in physical activity. This especially applied to those living alone as support tended to be short and time driven due to systematic underfunding of social care.

*“I think-people who are-people who again, are living on their own ...You know, unfortunately the quality of support that some people get erm, tends to be really time driven. You only have fifteen or twenty minutes...you know and they-if they're-they're doing the bare minimum-no-no that's not true, they're not doing the bare minimum, it would be essentials, yeah? And that means, things like social interaction, chatting...takes a back seat, because they're-there to make sure this is done and that's done that's done and all that...there's very little person led...support.. And that's not the fault, erm of the caregiver that's the system.”*  
(Bob, Manager)

One participant with a physical impairment did not get any support with cooking ready meals despite their difficulties. For most this meant they relied on informal support or ready meals. Participants, particularly carers, also noted the increasing gap in provision of day centres for adults with mild-moderate learning disabilities and less flexibility in support given. One family carer talked about the frustration of being offered support for her son to go running that did not materialise from two different sources despite being promised that this would be delivered.

Family carers also discussed having difficulties in finding out about appropriate resources available locally and the lengthy time, sometimes years, it took to get enrolled in these services. One summarised the obstacles that families often face in finding appropriate services for their loved ones with mild-moderate learning disabilities.

*“I think there are two issues. I think that the support, or the programmes that are available, are not advertised very well, at all. Erm and so most families don't know about them, er I think the second thing is that most of the work is focussed on people in residential care, er with more, er, severe disabilities. And there's very very little... support erm available for people who erm are living at home with their families.”* (Natalie, Family Carer)

Word of mouth was an important source of information for two family carers, but this involved proactive searching in the local environment and informal signposting such as by a family friend. However, some families may be unable to commit time and effort due to lack of awareness of benefits of healthy living or poor support networks. Additionally, this can have negative impact on funding services receive if this depends on level of uptake so this may create a negative cycle of funding cuts.

## 11.2 Other factors

Adults with learning disabilities can often experience discrimination and stigma related to their condition and this could impact health promotion efforts in local communities. For example, this meant that some adults with learning disabilities were reluctant to leave their homes due to safety concerns and hostility they faced from others. This limited their participation in physical activity in their local areas and led to greater social isolation. In other circumstances it was more subtle, for example, resulting in not being listened to by support services:

*“Every time I call them I’m on the phone and I have an argument with them I think they think I’m just a bit...She doesn’t know what she’s talking about, but when my sister’s talking to them on the phone they immediately listen and that’s what makes me angry-and it makes me very dependent.”* (Abayomi, Adult with Learning Disabilities)

Ableism was clearly an issue from this participants’ perspective in getting the support they needed, as their concerns and issues were disregarded when they tried to advocate for themselves but were attended to when presented by their able-bodied sister. It was clear she found this infuriating and it meant she was not given any meal time support, or helped at times when she fell due to poor balance. This may be a wider issue that prevents adults with mild-moderate learning disabilities accessing health promotion opportunities as it can silence them from expressing their wishes and desires.

A few participants suggested healthy eating was expensive. This also depended on brands of foods bought and for those with paid carers, if support was available to cook and store food in batches as this was considered ultimately less resource intensive. Again, this would require flexible support to be able to have longer cooking sessions on specific days for the following three to four days in the week.

Additionally, as more people move toward purchasing care, they may be reluctant to spend more money on individual rather than support with physical activity or healthy eating, but this would depend on need, budget and ability to relate to others. As many people with learning disabilities in supported living contexts do not have much control whom they live

with there is a reasonable chance they may not enjoy doing activities together. One paid carer noted this was a problem in his service.

*“Two service users at [Pine] are very different-one erm stays in, he doesn't really like going out whereas the other one goes out and he is very active and that has no effect whatsoever on the other-the one who stays in...He goes out. In fact he quite likes it when the other one goes out cos he's got the house to himself so...Oh and they don't get on, so they-they wouldn't [do activities together].”* (Dave, Support Worker)

Finally, bureaucracy was considered a significant barrier in implementing more creative plans to improve physical activity in paid care. A manager described how frustrating this could be for adults with learning disabilities as they needed approval of social workers and managers, if they wish to travel, for example, or wanted to adopt a pet. These measures are important, she noted, to protect vulnerable adults, and indeed ensure their ability to be responsible to animals, but this slowed innovation significantly.

## **12 Goal setting**

Many adults with learning disabilities in social care and day services participated in goal setting with carers through regular reviews, though they did not always define it this way, nor was this always formally done.

### **12.1 Proximal and distal**

Participants were asked what kind of goal setting was more important. Most, including adults with learning disabilities that understood this concept, felt both were important, but proximal goal setting more so for adults with learning disabilities. This related to their focus on short-term outcome expectancies when making food and activity choices to participate in and emphasis on tangible and achievable goals.

Progress would need to be reviewed regularly and one paid carer also stated some adults with learning disabilities do not have a great understanding of time and patience and would need more regular positive reinforcement whereas others could cope with longer intervals.

Important aspects of distal goal setting included goal strength and flexibility. One participant spoke about importance of helping a client discover an activity they valued highly so they would be motivated to overcome obstacles. Most carers also emphasised importance of flexibility because achievement would depend on factors such as emotional vulnerability and ability.

*“Yeah. And that’s less about, you know, how long it takes to get there, but it’s when they get there, when they’ve achieved that, that’s the key thing, when you’ve achieved that, then it’s okay make sure it’s being consolidated rather than just, it being a one off”* (Bob, Manager).

He also talked about importance of not setting a strict timeframe to achieve goals as it may take a person with a learning disability much more time to acquire some skills depending on their abilities. This participant also felt small achievements should also be praised, but these could easily be overlooked in favour of the ‘*big pay off*’, but it was also important to attend to these.

## **12.2 Monitoring progress**

Only three participants, all paid carers, talked about importance of monitoring weight of people they supported. For one, this was routine, whereas the other two mentioned this in context of weight loss goals set by carers along with pressure to maintain these dietary habits as participants did not always follow guidelines for healthy eating. However, another paid carer was highly critical of weight loss targets as she felt they were meaningless to some adults with learning disabilities:

*“I lost two pounds but I can’t see that, I can’t see it on me that I lost two pounds on me or whatever, d’you know what I mean?”* (Emily, Deputy Manager).

She stated weight loss goals were too abstract to have much impact on some clients and observed that some adults with learning disabilities might be very uncomfortable with participating in weight checks. This participant argued monitoring more experiential outcomes could be more helpful for a client. Another family carer shared this view, pointing out what positive effects someone with a learning disability might notice after making changes to their diet and activity levels:

*“Maybe more energy, erm you know perhaps their skin feels better... Yeah and energy levels perhaps and erm maybe just feeling less sluggish, that’s-that’s all about energy as well isn’t it, erm and not craving so much junk food”* (Leanne, Family Carer).

These included improvements in subjective and physical wellbeing as these are concrete and could act as reward for uptake of health behaviours, socially reinforced by praise and positive social contact with others. Participants also tended to favour more visual and experiential means, particularly using pictures, to mark progress as these could show gradual changes over time that a person may not remember or notice. This applied to improvements in wellbeing and gains in knowledge and skills. When asked, a participant with learning disabilities also responded very positively to this idea:

*“Yeah... Cos it would make me feel like I can do better things, and make me feel like just because I have one hand, doesn’t mean that I can’t cook”* (Abayomi, Adult with Learning Disabilities).

Thus, goal setting and monitoring could help participants improve their self-efficacy and positive outcome expectancies when adapted appropriately to this group.

### **13 Summary of findings**

Carers tended to have more detailed understanding of healthy eating and physical activity than adults with learning disabilities, but this varied widely with the latter group and some were able to explain how this might be achieved in some depth. A similar pattern emerged for explaining why this was important for health, with carers giving detailed rationales as to why promoting healthy lifestyles was important in supporting adults with learning disabilities. Some adults with learning disabilities described the benefits of healthier lifestyles in terms of benefits to physical and mental health, as well as importance for disease prevention, whilst others were more general in stating it could be good for health, but not giving specific rationales for this. Carers also varied widely in their understanding of sedentary behaviour. Very few demonstrated clear understanding of this as a distinct concept from increasing physical activity and most suggested increasing physical activity would decrease sedentary behaviour. A couple of carers suggested building decreasing sedentary behaviour into

routines to create new habits, such as by increasing other activities that involve standing or prompting adults with learning disabilities to set up their own activities, including bringing materials to the table for perusal rather than this being done by staff. There were several main findings exploring key themes in relation to how healthy eating and physical activity could be increased using social cognitive theory-based approaches (see Table 3 below).

Table 3: Key themes and Sub-themes on promotion of healthier lifestyles amongst adults with learning disabilities, including barriers and facilitators, for adults with learning disabilities and carers as appropriate

Population	Theme	Sub-Theme	Key Findings
Adults with learning disabilities	Self-efficacy	Increasing mastery	Mastery of procedural skills in relation to food preparation and cooking; activities that incidentally increase physical activity (e.g. gardening) Praise and recognition of achievements
Adults with learning disabilities		Positive role models	Staff or peers, celebrities they could relate to such as Paralympians
Adults with learning disabilities		Acting as role models	Positive role modelling for others such as peers or people they have a close relationship with
Carers	Self-efficacy	Increasing mastery	Increasing knowledge and procedural skills, mastery in cooking, how to promote healthier lifestyles and manage challenging behaviour with people they support, particularly in response to change. Consistency, firm boundaries and persistence in maintaining relationship key to managing challenging behaviour.
Both cohorts	Proxy-efficacy	Relationship quality	Trust, closeness, interest in wellbeing of adults with learning disabilities supports development of this toward carers, which enabled carers to make healthier choices (diet and activity) for people they supported). Important to manage emotional dependence, particularly amongst paid carers
Adults with	Outcome	Facilitating	Subjective, experiential outcomes such as hedonic pleasure of healthier food and

learning disabilities	expectancies	positive expectancies	physical activity, increased energy levels and better mood. Physical activity needs to be fun or purposeful, such as leading to employment, increased responsibility and status, or as form of travel.  Abstract concepts such as disease prevention or management not as persuasive or easy to understand though may be effective for some in context of 'health scare'
Both cohorts		Current (negative) outcome expectancies	Healthy food not as enjoyable or more effortful to make pleasurable than unhealthier alternatives.
Both cohorts		Other	Healthy eating strongly associated with weight management and body image
Adults with learning disabilities	Social Support	Positive social support	Person centred approach  Gradual support with change, particularly with rigid habits or behaviour  Carer self-efficacy in health promotion  Carer integrity in presenting options and consequences of lifestyle decisions  Carers being socially skilled in developing rapport with users  Carers motivation in supporting the person with learning disabilities with health promotion  Effective collaboration (within staff teams, between staff and families, with adult with learning disabilities)  Inclusive health promotion for all adults with learning disabilities and/or participating in health promoting activities with carers (e.g. communal healthy lunch)  Peer acceptance, mutual encouragement and accountability

Adults with learning disabilities		Negative support	<p>Cold, distant approach</p> <p>Misunderstanding ability levels, including over-estimating capacities of those with mild learning disabilities</p> <p>Disinterest in health promotion</p> <p>Other priorities due to desire to minimise distress or challenging behaviour</p> <p>Lack of communication between carers or services and family carers</p> <p>Over-promising services which then not provided</p> <p>Time and budget driven support in paid care</p>
Carers			Values and choice conflict: Importance of support with healthy living versus respecting the right to self-determination grey area with no easy answers for carers
Adults with learning disabilities	Goal setting	Goals	<p>Proximal goals more important</p> <p>Concrete, behavioural goals rather than outcome goals</p> <p>Small achievements</p> <p>Not rigid timeframe</p> <p>Consolidating achievements before moving to next goal</p>
Carers		Goals	<p>Distal goals useful for forward planning</p> <p>Flexibility important for effectiveness (timeframes, level of achievement, type)</p>
Adults with learning disabilities		Monitoring progress	<p>Monitoring subjective, experiential changes and achievements helpful according to most carers and adults with learning disabilities.</p> <p>Useful reinforcers are praise and quality time with carers</p> <p>Frequency of monitoring and reinforcement depends on individual memory,</p>

			<p>understanding and impulsivity</p> <p>Most carers perceived weight monitoring as too abstract or unhelpful and adults with learning disabilities able to answer this tended to not to favour this approach</p>
Adults with learning disabilities	Other barriers and facilitators	Personal Social Environmental	<p>Understanding, memory, attention, mental health issues, food sensitivities, physical health issues impacting mobility</p> <p>Availability of support, peer and celebrity influences</p> <p>Accessibility: Information, physical facilities</p> <p>Lack of opportunities for adults with learning disabilities</p> <p>Discrimination</p> <p>Safety of local environments impacting physical activity</p> <p>Limited financial resources</p>
Carers		Personal Social Environmental	<p>Time and resources to provide support including service closures</p> <p>Bureaucracy impacting creativity of support planning</p> <p>Difficulties in finding available services</p> <p>Varied perceptions of cost of healthy food</p>

## **Discussion**

### **Preferences**

Adults with learning disabilities showed high levels of reliability in their engagement with healthy and unhealthy food, and physically active versus sedentary leisure time pursuits. This also applied to those who did not prefer healthy options, but they disclosed these to the interviewer and this helped facilitate rapport for the interview. It also added some validity to findings by addressing concerns about social desirability bias in this group and gave some participants an opportunity to express their knowledge of healthy living using the pictures as communication aids.

### **Knowledge**

Both carers and adults with learning disabilities displayed some knowledge about healthy eating, able to give examples of healthy and unhealthy foods and cooking practices in accordance with wider public health messages. Responses given were consistent with public health recommendations such as aiming for five or more fruit and vegetables a day, consistent with Melville et al. (2009). Their knowledge about physical activity was also similar, with carers drawing on public health guidelines and adults with learning disabilities giving examples of different types of physical activity. Some adults with learning disabilities struggled to explain why healthy eating and physical activity were important, whereas others linked it to weight control, disease prevention and to a lesser extent, emotional wellbeing. This was similar to the findings of interview studies by Caton et al. (2012) and Kuijken et al. (2016) with this cohort. They found similar variability in depth of understanding from their participants with learning disabilities. Interestingly several paid carers and some adults with learning disabilities also drew upon the importance of health and safety knowledge in this context, also raised in previous research by Caton et al. (2012) and Rodgers (1998).

Carers also talked about their knowledge of the meaning of sedentary behaviour, which has not been explored in previous research in the field to this authors' knowledge. As expected this varied widely. Whilst a couple of participants were familiar with the term and why reducing this is important, others were not, though some were able to hazard a guess as to

what this meant. This is not surprising given the relative lack of public health focus on this area, as it has only relatively recently been defined in the literature (Melville et al., 2017). Their suggested strategies for reducing sedentary behaviour often relied on increasing physical activity as they tended to see it as a complementary process, including light physical activity such as walking.

However, it is thought that sedentary behaviour can be reduced simply by standing or chair-based exercises and has separate benefits for health other than increasing physical activity (Proper et al., 2011; Thorp et al., 2011; Tremblay et al., 2010; Wilmot et al., 2012). This means it could be potentially more inclusive of those adults with learning disabilities who are less ambulatory. Matthews et al. (2016) and Melville et al. (2017) found sedentary behaviours were indeed highly prevalent in adults with learning disabilities. Unlike physical activity, reducing sedentary behaviour may also involve less planning and cognitive effort as it can be done as part of other activities (e.g. standing whilst cooking). As a result, it may be easier to automate and integrate into a routine, such as by prompting service users to set up their own leisure activities or by bringing materials themselves to individual sessions within classes or at home. However, most carers were unclear how adults with learning disabilities could be supported to reduce their sedentary behaviour, suggesting education and training of carers may be needed to help them support clients to reduce sedentary behaviour.

## **Findings in context of Social Cognitive Theory**

### **Outcome expectancies**

The research findings, particularly in interviews with carers, strongly indicate that a key outcome expectancy to be accounted for when aiming to help adults with learning disabilities improve their diet is their immediate hedonic response to consuming food. Carers in the current study generally stated it was important to support adults with learning disabilities to make healthy foods that they enjoyed to increase their motivation to sustain behaviour change in this population. However, some participants appeared to feel that healthy foods were not as pleasurable as unhealthy alternatives and it would take greater effort to make them as palatable. Thus, it could also be important to address this in future interventions with staff to help change in their attitudes, such as including them in taste testing sessions. This is because

they can have significant influence on attitudes of people they support, through the choices they present when supporting them with their dietary intake (Smyth & Bell, 2006).

Short-term outcome expectancies were also seen as important motivators for adults with learning disabilities to engage in physical activity. Participants talked about benefits such as enjoying exercise, happier mood, increased social presence in the wider community were perceived as potential benefits of engaging people with learning disabilities.

Some participants, particularly carers saw this focus on short term outcome expectancies by adults with learning disabilities as a significant obstacle to effective health promotion with this group. They expressed concerns about depth of their understanding of long-term consequences of their choices. This is consistent with concerns raised by Smyth & Bell (2006) and qualitative research by Rodgers (1998) and Trip, Conder, Hale & Whitehead (2016) who felt they were in some ways *'lifestyle police'* of their clients with learning disabilities. Particularly in the latter study participants were unsure where their responsibilities stopped and client ownership of their own decisions began. In other studies, staff have also spoken about the importance of respecting client choices regardless of the consequences (Cartwright et al., 2015; O'Leary et al., 2018; Spanos et al., 2013). Whereas O'Leary et al. (2018) argued this could be disempowering for them when promoting healthy eating with this client group.

Participants with learning disabilities particularly felt that self-motivation to engage in physical activity was important for their cohort to initiate participation in exercise. They felt that support from others could build on this, but not replace it. This has also been found by Mahy et al. (2010) Ruud et al. (2016), van Schijndel-Speet et al. (2014) in their studies with adults with learning disabilities and paid and family carers. However, similar to Caton et al. (2012) and Kuijken et al. (2016), this study found a significant proportion of adults with learning disabilities did want to eat healthily and be active because they cared about the health benefits of doing so. They expressed desire to prevent disease and linked these behaviours to feeling happier and less anxious, as well as better performance. Some were quite passionate about this. The adults in the current study were recruited from varied settings through visits to local services and word of mouth unlike participants recruited by Kuijken et al. (2016), who were recruited by advocacy groups. This suggests concerns about healthy living amongst adults with learning disabilities could be wider spread than previously thought. The research indicates some carers in the current and previous studies may have

under-estimated the interest of adults with learning disabilities in participating in health promoting behaviour (Spanos et al., 2013).

Some carers perceived improving diet as a greater priority than increasing physical activity as they suggested it may be more inclusive for adults with learning disabilities. This was due to some having physical impairments precluding participation in the latter. A survey by Melville et al. (2009) also suggested carers saw this as more important for their clients. Weight concern was a common theme in several interviews with carers and adults with learning disabilities; several constructed healthy eating as a priority for those with overweight or obesity, echoing research by O’Leary et al. (2018). From perspectives of some paid carers and managers this could make it difficult to engage with clients’ families as they could react negatively if professionals tried to involve them in health promotion efforts. They suggested this was partly due to fear of blame toward their social and cultural practices and that it would be better for health professionals to promote healthy eating for all clients as this would not single out individuals in the process. This could then lower defensiveness from families and have wider impact on this vulnerable client group as a whole.

Interestingly, a key novel finding in this current study was that there was also pressure, particularly from some adults with learning disabilities, to eat well for positive body image. The link between the two was so pervasive one participant was reluctant to eat healthily because they could be perceived as having an eating disorder by friends and family. However, improvements in body image from eating healthily were viewed as a potentially meaningful and tangible outcome by some carers to keep adults with learning disabilities motivated to engage with it, including others noticing weight loss. This contrasts with Melville et al. (2009), where only a minority of carers saw improvements in body image as a benefit of eating healthily and doing exercise for their clients with learning disabilities. Nevertheless, this is supported by Bandura (1986) as he argued that whilst material rewards may initially cause a person to engage in a behaviour they may not otherwise consider, their sustained involvement in that behaviour could be replaced by intangible social rewards. This includes praise and recognition of achievement and in this context, others making positive comments on appearance, reinforcing health promoting behaviour by adults with learning disabilities.

The final key outcome expectancy for engaging with healthier eating and physical activity was that adults with learning disabilities perceive activities as purposeful and meaningful.

They were keen to do activities that could help them develop their practical skills, for example to create opportunities to get a job, or to help others such as by cooking a meal for a friend, work within a wider team or gain responsibility and status amongst their peers. Interestingly, this was also found by van Schijndel-Speet et al. (2014). In their interviews with older adults with learning disabilities, a common motivator for doing physical activity was doing something meaningful to help others, such as by litter picking or helping others in their local neighbourhood. Some participants in van Schijndel-Speet et al. (2014) preferred doing this to recreational sport because they sometimes felt the latter was '*childish*' and inappropriate. Some in the current study still played sport and enjoyed this but these participants were younger to middle-aged adults. One paid carer in the current study also stated that the older adults they supported viewed themselves as being in retirement and thus no longer needed to be involved in swimming and sports. A developmental perspective would then perhaps suggest that some older adults would no longer view sport as relevant. This is not necessarily exclusive to adults with learning disabilities but may also reflect wider social narratives around retirement and relaxation.

### **Self-efficacy**

Improving skill mastery was thought to be important to increase self-efficacy in adults with mild-moderate learning disabilities, which is consistent with Bandura's' (1986) original conceptualisation of how this could develop over time. However, this can be particularly challenging amongst this group due to their cognitive difficulties in understanding and memory as well as greater prevalence of co-occurring physical impairments in this group. Thus, giving this group longer, flexible timeframes to achieve mastery over time is important. However, most previous interventions with adults with learning disabilities have not attempted to increase self-efficacy in this group because it can be challenging (Conner & Norman, 2015; Willems et al., 2017). As this can be time and resource intensive, future interventions may also benefit from training carers to support skill development amongst adults with learning disabilities alongside direct work with this group.

Carer mastery was also important and could be improved with greater knowledge of healthy eating and physical activity, especially by developing their skills, knowledge and experience in cooking. Both adults with learning disabilities and carers noted how important this was in the current study for healthy eating of the people they supported. A significant number of

paid carers in particular come to the field very inexperienced in this and training is not widely available in social care. Staff interviewed by Spanos et al. (2013) and O’Leary et al. (2018) also suggested it was important to train staff in principles of a balanced diet and cooking as relatively few had experience doing so before working in the field or did not do so for themselves. Bergström et al. (2014) achieved some success through this approach though staff also required ongoing support in supporting adults with learning disabilities effectively with behaviour change.

Role modelling could be important to improve self-efficacy of adults with learning disabilities. Peers such as friends, siblings or fellow volunteers with learning disabilities could be powerful role models for this group, supporting the use of peer mentors in interventions. This provides support to the intervention developed by Bazzano et al. (2009) as they primarily had peer mentors to deliver support to users of the group. Some paid carers also suggested support workers could also be important role models for their clients. This could be positive if staff were motivated to act as healthy role models for clients, but it was noted it could put pressure on carers to maintain this image. This could be problematic if they could not live up to client expectations or were unwilling to take on this role with their clients. This was also noted by Dixon-Ibarra et al. (2017), in their study on barriers and facilitators to physical activity, as staff role modelling healthy behaviour could have a significant positive impact, whereas staff disinterest also had a strong negative impact on clients.

In the intervention by Bergström et al. (2014) certain members of staff acted as role models for healthy living in their services. This could be a useful avenue for future interventions if staff members are willing to take on this position, as it allows for greater autonomy on their part and a more specialised role in finding out and sharing information. It would be important that they do not have an excessive workload in the process, however, or be perceived as solely responsible for promoting health as this could be discouraging and lead to disengagement by staff and inconsistent support to users. Mahy et al. (2010) also found a barrier to increased physical activity amongst adults with learning disabilities was their need for a lot of encouragement, which could be emotionally draining for staff. This was echoed by a carer in the current study who spoke about the great effort it took her to successfully motivate a client to visit the gym, by helping them visualise emulating action heroes in popular culture. This happened weekly on an ongoing basis. Another participant discussed

the move toward values-based recruitment in their organisation. This may potentially be encouraging if staff see health promotion as an important part of their caring duties rather than optional (O'Leary et al., 2018; Smyth & Bell, 2006) and therefore willing to persist in their efforts. Staff training may also be important to encourage this (Bergström et al., 2014; O'Leary et al., 2018).

It must be noted that celebrities were not often endorsed unequivocally as role models by either adults with learning disabilities or carers, as they were seen as both positive and negative influences on behaviour. Paralympians were suggested as an exception to this. However, a paid carer and a participant with a learning disability both noted the importance of having adults with learning disabilities being positively represented within the media, including in mainstream cooking programmes, something that is currently lacking.

Recognition was also important for improving self-efficacy in this group. Receiving praise for achievement was universally agreed by carers to be an important source of self-efficacy for adults with learning disabilities. This could include when introducing healthier foods and activities to adults with learning disabilities, which can be particularly difficult if they have certain food sensitivities or physical disabilities which act as barriers to participation (Bergström et al., 2014; Spanos et al., 2013). It could also be used more generally to support them to maintain effort with difficult tasks. Additionally, Dixon-Ibarra et al. (2017) and van Schijndel-Speet et al. (2014) found that winning and having rewards such as trophies also motivated some adults with learning disabilities to participate in physical activity.

Interestingly, this study suggests being a role model for other adults with learning disabilities could potentially be an important source of self-efficacy for this group. For example, by leading an instructional healthy cooking video or how to perform a physically demanding task could increase confidence by demonstrating skills to help others and thus increased mastery (Bandura, 1986; Bandura, 2001). This may need empirical investigation in future research. The only caveat to this is that when appraising performance in public, self-perception may be less accurate due to pressure to be modest or self-flattering and gain status. Thus, informative feedback is also important (Bandura, 1986) when role modelling positive behaviour to others.

## **Proxy efficacy**

Bandura (2001) also theorised that individuals also develop a sense of proxy efficacy in others' mastery of key skills they may not have the time, resources or ability to develop themselves as this enables greater efficiency in organising daily living. The current study has been the first, to this authors knowledge, to explore how this may be present in the relationship between adults with mild-moderate learning disabilities and carers as this construct has not been widely investigated in previous research. It was widely acknowledged that adults with learning disabilities often need support from others with daily activities, such as with shopping, cooking, accessing opportunities for recreational physical activity. This has also been noted in previous studies (Caton et al., 2012; Kuijken et al., 2016; Melville et al., 2011; Rodgers, 1998; Smyth & Bell, 2006; Spanos et al., 2013). What also emerged as important in the current study, however, is the quality of the relationship between carers and the people they support. Adults with learning disabilities needed to be able to trust their carers to support them, to fully engage with them and rely on them as proxy decision makers. Proxy decision making involved aspects such as understanding what constitutes healthy eating and helping adults with learning disabilities with related aspects such as shopping for groceries or budgeting. Therefore proxy efficacy was important (Bandura, 2001).

Taking time to build trust and show warmth and empathy towards adults with intellectual disabilities was important to build a sense of proxy efficacy. Several suggested this could be key in engaging them in healthier eating and physical activity and managing challenging behaviour when it arose. Future interventions would benefit from exploring the relationship dyad between carers and adults with learning disabilities to enhance these as appropriate in the context of health promotion. Care should also be taken however, not to encourage excessive emotional dependence on carers on the part of the person with learning disabilities. This is because they may come to over-rely on those persons to provide emotional and practical support to engage in health promoting behaviours to exclusion of others providing support. In this context it may be important for service users to have an opportunity to see newer staff shadow or be instructed by more experienced staff on how clients preferred to be supported. This could help build trust and a stronger relationship with newer staff through alleviating some of the anxieties they might have and aid effectiveness in health promotion efforts.

## **Social support**

This study found that social support could be both positive and negative from carers and peers of adults with learning disabilities. Sources of positive social support from carers came from having high levels of self-efficacy and motivation to support adults with learning disabilities with healthy living, alongside a warm, empathic manner. Being person-centred and actively involving adults with learning disabilities in their own care planning was widely considered important by participants. These findings were supported by Marshall et al. (2003), Melville et al. (2011) and Spanos et al. (2013). This could be perceived as support for autonomy (Pelletier & Joussemet, 2017). A previous intervention by Melville et al. (2011) provided individually tailored support to adults with learning disabilities and carers worked for most participants precisely because it offered the use of person centred resources (Spanos et al., 2013). Other important factors raised in the current study were being flexible and supporting gradual behaviour change. This was especially helpful for those with long ingrained habits or who had additional conditions such as autism, which could result in rigid behaviour preferences. For example, they felt gradual changes in routine, or close substitutions for familiar foods or eating patterns could work well for those who struggled with this.

Another important facet of positive social support was the use of clear boundaries and consistent support, particularly by paid carers. Clear boundaries were perceived as important for managing relationships with clients so they stayed professional rather than being misinterpreted as friendship, without losing compassion and warmth. Consistent support could help clients receive similar messages from different staff about healthy living and maintain clear understanding of what was expected of them. For most carers consistency in the staff team supporting the person to live healthily mattered more, but for one paid carer consistency in routine was of greater importance. Consistency and stability in staff team was perceived as a facilitator to weight loss by adults with learning disabilities in Spanos et al. (2013). Carers in the current study linked consistency and clear boundaries to adults with learning disabilities feeling safe, knowing that staff had read their care plan and supported them according to this, so they at least knew what to expect.

This also came through collaborative working. As suggested earlier, adults with learning disabilities could sometimes benefit from seeing a carer they trusted working with newer staff

to demonstrate examples of good practice. Some adults with learning disabilities may become involved in showing new staff how to support them and quite enthusiastic about this. It may also be important for paid staff to collaborate with family members of clients to avoid de-skilling the person by perceiving a need to conduct all tasks for them. This may also be welcomed by some families according to the current study as it could improve their own knowledge and confidence in supporting their loved ones in their home environment. Collaboration was not always possible when there was a mismatch between aims of paid carers and families they worked with, consistent with research by Cartwright et al. (2015) and O’Leary et al. (2018). This could cause tension and conflict, not just between staff and families, but within families themselves. Open dialogue with families, open emphasis of the role of the paid carer in supporting their clients’ needs and desires, presenting positive case studies of past successful support for clients to families and understanding their concerns could be useful for collaboration, to build trust and a working relationship. As carers in Spanos et al. (2013) and Cartwright et al. (2015), noted, carers could trivialise the importance of healthy eating and physical activity due their clients’ learning disability. This involved ‘*treating*’ their clients, comforting them with food and resulting in mixed signals or confusion from clients and undermining efforts by others to promote a healthy diet.

There were examples of negative social support described by adults with learning disabilities, for example when living in a group home but sharing the same meals as other housemates which resulted in dissatisfaction. Likewise, a participant interviewed in the study by Kuijken et al. (2016) expressed frustration with a carer that had made a meal for the group of people they lived with as it was not something they enjoyed themselves. This person would then have a takeaway during that time instead. It must be noted that adults with learning disabilities do not often have any choice about who they live with and some may not enjoy each others’ company. This can act as a barrier to mutual social support or setting up group activities, though these may be less resource intensive for service providers.

Another significant source of negative social support for adults with learning disabilities receiving support within the social system was generally attributed to budget and time driven support. There were widely held perceptions in the cohort that social care was underfunded, contributing to poor staffing and accessibility of opportunities for adults with learning disabilities. These are findings supported by Caton et al. (2012), Dixon-Ibarra et al. (2017) O’Leary et al. (2018) and Mahy et al. (2010). This meant that some adults with learning

disabilities, particularly those with milder learning disabilities, would not get adequate support to shop for, cook, store and heat healthy food safely. They would also not have access opportunities for recreational physical activity unless they could do it by themselves. Echoing these findings on a large scale, Stancliffe & Anderson (2017) found being able to access opportunities for recreational physical activity independently was a significant predictor of participation amongst a sample of adults with learning disabilities.

Carers also noted that others were not always motivated to help improve the eating habits and activity levels of people they supported. Carers sometimes prioritised attending medical appointments rather than ongoing support with health promotion per se or appeared to perceive healthy eating as '*boring*' or requiring greater effort to be palatable which could result in it not being a priority when cooking meals with and for the people they supported. Marks et al. (2013), in their intervention, taught staff to explore pros and cons of behaviour change to change their outcome expectancies as part of their intervention. This is common when delivering motivational interviewing interventions to resolve ambivalence. They found end users of the intervention engaged in healthier eating and physical activity at the end of it.

Support by peers was more often characterised as negative than positive by carers and a couple of adults with learning disabilities in the sample, particularly due to peer pressure. This especially related to consuming fast food. It also meant that some may perform behaviours they may not have been motivated to and manifested as eating contests at buffets according to some carers. This was considered convenient, cheap, familiar and palatable. Kuijken et al. (2016) noted that adults with learning disabilities in their sample seemed highly susceptible to both positive and negative influences of others, which was supported by the current study.

The other, darker, element touched upon by some carers and adults with learning disabilities, was their vulnerability in wider society. This seemed particularly to apply when they participated in physical activity, that could result in abuse and exploitation. Alternatively, peer encouragement could be powerful in enabling participation in health promoting behaviours. For example, having friends participate in taste testing palatable healthy foods was considered highly persuasive in encouraging engagement by adults with learning disabilities with healthy eating. The willingness of friends to follow the lead of an adult with learning disabilities with a physical impairment in a sport session was another instance. This

could also be important for self-efficacy and positive outcome expectancies regarding activity enjoyment for future participation for an adult with learning disabilities in this context. However, some participants with learning disabilities in the current study had strong negative perceptions of those they regarded as overweight, having poor diets and low levels of physical activity. This may result in '*policing*' or criticising peers, which may not be helpful when aiming to promote healthy eating and physical activity with adults with mild-moderate learning disabilities. Future group interventions may be more successful if they address this by teaching them strategies to provide positive mutual support, including praise for achievement, discouraging punishment for perceived failures and encouraging peer learning. It may be achieved through experiential means such as by group learning, role play and social story telling. This will need to be done with care to ensure these strategies are within the abilities of individual group members and do not place them under excessive pressure.

### **Goal-setting**

Participants with learning disabilities struggled with the concept of goal setting, but those in social care set goals as a routine part of their support, such as in person centred reviews. They reported that this was useful. Carers were asked about the usefulness of short-term versus long term goals. There was a general consensus that whilst both were useful, short-term goals were more meaningful to adults with learning disabilities as they tended to be more tangible and associated with more immediate feedback. The same argument was also made by Bandura (1986) for adults in the general population and the current study suggests this can also be extended to those with learning disabilities. Long term goals provided more structure for short-term goals to work towards, but carers stressed importance of having flexible expectations, including timeframe, to achieve these. Being realistic about what could be achieved in the context of the clients' abilities was also emphasised. Feedback and positive reinforcement were also considered important, but they felt frequency of this depended on the individual, due to variation in memory and their understanding of time.

Pictures were considered quite useful, particularly by paid carers, for feedback as these were experiential and made it easier for adults with learning disabilities to monitor changes over time and recall what they had done to achieve their goals. Quality time with preferred staff, special treats such as days out or being pampered were considered helpful rewards by one staff member who informally supported several service users to participate in a weight loss programme for six months. Other interventions have used rewards such as medals (Marks et

al., 2013) and attendance certificates as rewards and reinforcements for participants (Chow et al., 2016).

As discussed earlier, one of the key outcome expectancies for adults with learning disabilities to participate in healthy eating and being more active was having a sense of purpose and meaning from their activities. This also relates to setting achievement related goals. Some carers, particularly paid carers, attributed importance to recognising behavioural achievements by their clients, including small gains in skill that could be overlooked. This was by, for example, breaking down the task of cooking a meal, and noting when a person had been able to boil a pan of water independently in the process. This was considered something that could easily be unnoticed or taken for granted if not attended to.

Consolidating knowledge and skills adults with learning disabilities had developed would be the important next step. This relates to praising the client for their achievements and increasing their sense of self-efficacy. Carers valued setting goals that would support adults with learning disabilities to achieve greater mastery according to their abilities, rather than demonstrate competence to others (Bandura, 1986; Elliot & McGregor, 2001). Actual mastery may be more important in helping them gain independence in this area, something valued particularly by participants with learning disabilities themselves. This also suggested the importance of supporting adults at their own level of competence (Smyth & Bell, 2006), rather than that desired by others, which may help in provision of person centred support to this group.

### **Other factors**

Family carers strongly felt that there were not enough resources for adults with learning disabilities living with their families. They also related their struggles to find opportunities for adults with learning disabilities to participate in their local communities, such as in physical activity as these were poorly advertised. This is not surprising as these may not have much funding to inform wider communities of their existence, but for three out of four family carers, their stories suggested that they had found opportunities for people they supported through luck and determination, over several months of searching and relying on word of mouth. Another noted that this issue had become worse in the previous three years as a result of closures of services. Matthews et al. (2016) also noted this contributed to lack of success of their physical activity intervention, which was based in Scotland, in significantly

increasing participant walking distance, due to similar funding cuts. Additionally, as also pointed out by another family carer, families may not always have the time or motivation to search for opportunities over a sustained period due to other priorities. They may also perceive this as difficult and provision of services was noted to be widely variable by a participant facilitating access to recreational physical activity opportunities for adults with learning disabilities.

Some participants also raised concerns about the lack of support adults with learning disabilities receive to develop their cooking skills. This was attributed to lack of time and flexibility to meet the needs of this group, as their abilities were widely heterogeneous. One argued that a more relaxed learning environment, including one-to-one peer learning, could be more appropriate. They also noted carers tended to do cooking for adults with learning disabilities which restricted opportunities for skill development, partly due to health and safety concerns.

Concerns about health and safety have also resulted in adults with learning disabilities having restricted involvement in cooking according to previous studies (Caton et al., 2012; Rodgers, 1998). However, this could be an anxiety provoking experience for some adults with learning disability cooking due to cognitive and physical impairments which can be commonly experienced in this population (Bergström et al., 2014). This individual, however, did not receive support to cook from her carers, as she had a very restricted support budget from social care services, though she was very eager to learn properly. As a result, she may have benefited from practising her skills, using observation and visual aids, or equipment or recipes adapted to her needs as she had an additional physical impairment and difficulties understanding time. For example, she could have learned to cook one pot meals in a slow cooker, made blended soups, as these are examples of meals that may involve less time monitoring and risk.

### **Bureaucracy and organisational processes**

The final barrier, mentioned by several paid carers in particular, was of bureaucracy and organisational processes, making it difficult to implement health promotion initiatives creatively and considerably slowed down the process. This could stop users from taking spontaneous trips to try new activities, have a pet or obtain staff support to attend activities

around their needs and goals, such as evening sports sessions. Staff also often had a limited budget to go out with service users, which meant that most healthier options when eating out were not considered as these were more expensive and the client may not have had the budget to afford healthier options themselves. As both staff and service users tend to be of lower socio-economic status, this could restrict their choices in these contexts (Smyth & Bell, 2006). However, interestingly Stancliffe & Anderson (2017) found those adults with learning disabilities that went out to restaurants, amongst others, were four percent more likely to meet physical activity guidelines than those that did not in their US study. This is a relationship that may need further unpicking. Bureaucratic obstacles could also partly explain difficulties family carers in this study had in getting support for their loved ones as planned support packages were not implemented. This was accompanied by little or no communication by local organisations offering support with one of them during this process. These were frustrating experiences for this group. Previous research by Ruud et al. (2016) touched lightly upon organisational issues faced by carers, but did not expand on these.

### **Social Cognitive Theory and Self-Determination Theory**

Previous researchers have suggested integrating social cognitive theory (Bandura, 1986; Bandura, 2001) and Self-Determination Theory (Deci & Ryan, 2000). This is because whilst the latter explores antecedents to motivation for individuals, the former explores the wider social and environmental contextual factors impacting behaviour (Conner & Norman, 2015). Social cognitive theory also incorporates goal setting and planning, to help people translate intentions into behaviour (Conner & Norman, 2015). Overall, the findings of this study support such a move.

Firstly, this is because several carers and adults with learning disabilities spoke about the importance of doing activities that individuals enjoyed, especially in relation to physical activity. Thus, individuals would have sufficient intrinsic motivation to overcome obstacles to behaviour change, particularly in sustaining healthy behaviours. One paid carer also spoke at length about how finding this activity this could improve their clients' well-being and sense of self-worth, and lead to intangible social rewards such as praise and recognition. Ryan and Deci (2000) argued that participating in activities that individuals found highly intrinsically motivating would lead to increased subjective wellbeing and self-worth. This is because, they argued, individuals are growth oriented, and these activities fulfil human needs for increased competence, autonomy and relatedness.

There was also emphasis in this study on creating opportunities for adults with learning disabilities to participate in purposeful activities, such as gardening, to increase their physical activity through mastery of knowledge and skills. A manager in a gardening centre also described giving some of his more skilled and independent volunteers with learning disabilities opportunities to work autonomously, including leading peers in certain tasks. They were expected to meet the needs of the business, but most received praise for their performance. Receiving praise, or recognition for achievement, was perceived to be important to improve outcome expectancies and sense of self-efficacy by several paid carers in the study. It could be argued that creating these opportunities to work independently would have increased extrinsic motivation that the individuals were able to integrate into their values and sense of self. Thus, they would have been highly motivated to maintain this behaviour with few extrinsic rewards (Deci & Ryan, 2000).

Previous research by Pelletier & Joussemet (2017) also suggests autonomy support for adults with learning disabilities increases their perseverance in and perceived value of unpleasant tasks. They achieved this by communicating with participants in an empathic, non-coercive manner, giving them a choice of task whilst retaining structure and boundaries in their approach. Participants in the current study talked about the importance of adults with learning disabilities being involved in health promotion. This included providing input into their diet and physical activities (autonomy), using a warm and friendly approach (empathy), being non-coercive and having consistency, structure and appropriate boundaries in place. This was considered important in addition to self-efficacy. It may also be important in explaining why addressing proximal outcome expectancies may be a priority with adults with learning disabilities regarding healthy eating, physical activity and sedentary behaviour.

Deci and Ryan (2000) also argued that social and environmental influences that create conflict between basic human needs can create mental health issues for individuals. The current study and previous research suggests a high value is put on independence and choice for adults with learning disabilities (e.g. Smyth & Bell, 2006 but this can be at the expense of their need for relatedness and competence. This is because several carers raised concerns about adults with milder learning disabilities being assumed to have greater capabilities than they do and having minimal support if they were living alone. This could lead to isolation and a lack of help to develop mastery.

One issue to consider, however, is that perceived competency and sense of self-efficacy may not always match (as noted by Deci & Ryan, 2000). Indeed, whilst SDT argues that individuals strive to grow and develop, not all participants agreed with this. Some felt that some adults with learning disabilities enjoyed being cared for. They may not always be motivated to develop their skills due to the perceived efforts involved. Additionally, as one manager stated, some volunteers were content to carry out simpler tasks they found purposeful as it was within their capabilities, rather than striving for increased competence. Bandura (1986) argued that individuals may sometimes persevere with achieving a previously met standard if they feel able to repeat this, rather than a higher standard carrying risk of failure and subsequent disappointment, as part of their self-efficacy assessment. Thus, social cognitive theory (Bandura, 1986; Bandura, 2001) provides a better fit to the data in this regard.

Another issue to consider is that a need for relatedness was considered by Deci and Ryan (2000) to be a more distal causal factor for motivation than competence and autonomy. It could be argued that this is not the case for adults with learning disabilities as they rely on carer support with everyday living. Social Cognitive Theory (Bandura, 1986; Bandura, 2001) is more detailed in how this can influence behaviour, through considering positive and negative social support as well as influence of proxy efficacy.

Thus, Self-Determination Theory (Deci & Ryan, 2000) can be used to set out the underlying conditions to increase motivation to do an activity (Pelletier & Joussemet, 2017). Social Cognitive Theory (Bandura, 1986; Bandura, 2001) can then also be used as the framework to translate this more effectively to behaviour change within the social context adults with learning disabilities often live in.

### **Strengths and limitations**

This is the first time, to this authors knowledge, that a theory-based approach has been used to interview adults with mild-moderate learning disabilities and their carers about how healthy eating and physical activity could be improved in this cohort. There has not been any previous research with adults with learning disabilities using this approach, potentially due to concerns regarding their ability to engage meaningfully with complex theoretical constructs. However, an iterative approach involving carers and adults with learning disabilities was particularly useful for engaging them in this research, alongside development of vignettes for

this group. These adaptations proved helpful in two ways for this group. Firstly, complex constructs were explored in depth with carers, followed by early transcription and preliminary analysis. This enabled generation of specific ideas that could be tested with adults with learning disabilities where appropriate if they struggled with open-ended questions. Secondly, vignettes were also used to simplify questions about theoretical constructs with adults with learning disabilities and make them more tangible, particularly earlier in the study when data generation was more open-ended. These steps proved highly effective in generating data with this group and including them in this research, which is very important in understanding their health needs from their own perspectives.

Secondly, this study used social cognitive theory (Bandura, 1986; Bandura, 2001) as the underpinning model for this interview study. This was because it considered personal, social and environmental factors which could impact behaviour change in this group. As a significant proportion of adults with mild-moderate learning disabilities rely on carers' support to be able to access health promotion opportunities it is important to consider this for future intervention development. More specifically, Bandura (2001) discusses the importance of having a sense of proxy efficacy in others' mastery of key skills, and this study was the first, to this authors knowledge, to explore how the relationship between adults with learning disabilities and carers could impact this in the former to impact health promotion. This study was also the first to explore ways in which self-efficacy may be improved in adults with learning disabilities according to the perspectives of this group and their carers, which may be tested through intervention research to understand if and how this may be feasible (Willems et al., 2017).

Only one other study has used a theory-based approach to interview staff within this area (O'Leary et al., 2018). They used a trans-theoretical model-based approach to understand organisational barriers and potential enablers to health promotion with adults with learning disabilities within paid support services. In contrast, the current study focussed on gathering data to support uptake of healthier behaviour through guiding implementation of interventions with adults with mild-moderate learning disabilities. There were several differences between the research by O'Leary et al. (2018) and the current study. Firstly, the former only interviewed paid carers of adults with learning disabilities, rather than involving family carers in the study. Additionally, they examined '*capacity*' to promote healthier lifestyles amongst adults with learning disabilities as a cohort, rather than mild-moderate learning disabilities specifically. As discussed earlier, there are differences in health

behaviours between adults with mild-moderate learning disabilities and those with more severe learning disabilities, including differences in diet and physical activity uptake. As such, the current study had a more specific focus in this respect. Additionally, whilst the former explored organisational factors which may impact health promotion efforts by staff, the current study explored individual, group and wider social and environmental influences on health promotion with this group. It also explored with participants what may aid uptake of healthy eating and physical activity using those theoretical constructs to guide questions with this group rather than theorising what could help address organisational barriers after interviewing staff about the key issues involved, so was more direct in involving their perspectives. This may facilitate intervention development and implementation in a more inclusive manner, with specific recommendations that may facilitate hypothesis testing and implementation research with this cohort and their carers.

Finally, this study also aimed to inform training content for paid carers directly supporting clients with mild-moderate learning disabilities to engender behaviour change, rather than seeking to influence organisational policy and culture. This included engendering effective emotional and practical support, and their role as proxy decision makers at times for the people they support. This may facilitate more effective use of social cognitive theory (Bandura, 1986; Bandura, 2001) in individual and group contexts, though this remains to be tested.

The current study is one of the few to explore the understanding of both adults with learning disabilities and carers on what constitutes healthy eating and physical activity in depth. This is also the first to the authors knowledge to examine carers understanding of the nature of sedentary behaviour and how this can be reduced with adults with learning disabilities, as a relatively new area in the field (Melville et al., 2017). In this way the study aims to add to the growing body of research with adults with learning disabilities and carers on their perspectives regarding the health needs of this group. The current study also supports many of the findings of previous research in the area.

This study also recruited a significant number of carers and participants with mild-moderate learning disabilities from different contexts, including both family carers and staff working with this group. Most carers had a significant amount of experience supporting a person with a learning disability. Several also worked with a significant number of clients as professionals

over time so were able to give rich data into what may be useful for future intervention development.

The understanding of adults with learning disabilities varied widely between participants in this study and it was not always possible to gauge this at the outset. It was also notable that carers were widely unavailable to attend interviews with participants with learning disabilities, due to time constraints. This did not prevent participants from wanting to participate. Nevertheless, this may have been important for some participants to be able to understand questions and communicate more fully in the interviews, something that may need to be encouraged in future studies.

It was also difficult to keep them focussed, at times, on the topic at hand. Memory, understanding and concentration issues at times made it difficult for them to remember key information and respond to the questions they were faced with, with relevant answers. At times they appeared to try to respond with answers they felt the interviewer was aiming for, which may be due to the desire to appear to have the skills and knowledge needed to be able to carry out health behaviours independently (Smyth & Bell, 2006).

The use of vignettes had mixed success. These enabled a breakdown of complex ideas for adults with learning disabilities to enable meaningful participation in the interview, yet their understanding varied greatly around different aspects of the vignettes. Most participants were able to discuss their learned behaviours around their diet and activity but some struggled with psychological aspects of dealing with these issues. This included what helped build trust in staff to support them with these issues and gain confidence to cook and eat more healthily. The use of pictorial aids could only help to an extent to discuss these issues but forced choice alternatives were considerably easier for adults with learning disabilities.

Thus, an iterative approach to interviewing was a very useful one, as the data from carers proved useful in asking specific follow up questions of adults with learning disabilities, which they engaged with more easily than with open questions. This was followed by cross-checking further ideas from the latter group with carers in a cyclical pattern and then a final group of adults with learning disabilities participated to explore follow up ideas from the carer sub-sample. This was not, however, done in a very systematic way, particularly in earlier stages of data collection, but driven by participant availability for recruitment into the study from a particular service. This approach can lengthen the recruitment process, but it enabled better data saturation for the themes explored.

Another issue with using vignettes is that, like with some quantitative surveys tapping into SCT-based constructs with participants, it was very difficult to ensure that the questions asked tapped solely into constructs intended and not into related ideas instead (Marie et al., 2014). As such these were only useful when initially exploring these ideas with participants, but not for later interviews as specific ideas of how to improve self-efficacy, for example, had been suggested by participants by then. Therefore it was more appropriate to explore specific ideas with participants such as how role modelling could be implemented for to improve sense of self-efficacy.

In future it may be possible that virtual reality-based or enactive scenarios may be used to explore these ideas with adults with learning disabilities, particularly, in a more experiential way. These could aid their understanding of the topics being investigated and explore their behavioural response to these situations in greater detail. This would need to be done with care, to help them engage with important aspects of situational scenarios and facilitate better exploration of psychosocial aspects of healthy eating, physical activity and sedentary behaviour in this group.

## **Conclusion**

This study suggests improving outcome expectancies by focussing on more immediate benefits of healthy eating, physical activity and reduced sedentary behaviour may be effective. Self-efficacy could also be increased through providing opportunities to increase mastery, provision of role modelling as well as giving adults with learning disabilities opportunities to be role models and supporting recognition of achievement. Carer self-efficacy may be improved through increasing knowledge in nutrition, physical activity and sedentary behaviour and how this may be applied with the people they support, particularly for paid carers. This may also involve providing support in managing challenging behaviour. Increasing proxy efficacy may also be important amongst adults with learning disabilities through building trust and rapport with carers so they can support them effectively with behaviour change, but emotional dependency also needs to be managed. This study also suggests short term goals are relatively more important and meaningful to adults with learning disabilities, though both proximal and distal goal setting both have a role. Finally, monitoring small gains in skill and bigger achievements seems to be important for providing meaningful feedback to this group, as well as noting changes in behaviour. The usefulness of

communicating changes in weight related outcomes, though routine in a couple of instances, may be too abstract for some adults with learning disabilities to understand and carry stigma.

## References

- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179-211.
- Aune, D., Norat, T., Leitzmann, M., Tonstad, S., & Vatten, L. J. (2015). Physical activity and the risk of Type 2 diabetes: A systematic review and dose–response meta-analysis. *European Journal of Epidemiology*, 30(7), 529-542.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, N.J: Prentice-Hall.
- Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, 52(1), 1-26.
- Bartlo, P., & Klein, P. J. (2011). Physical activity benefits and needs in adults with intellectual disabilities: Systematic review of the literature. *American Journal on Intellectual and Developmental Disabilities*, 116(3), 232-232.
- Bazzano, A. T., Zeldin, A. S., Diab, I. R. S., Garro, N. M., Allevato, N. A., & Lehrer, D. (2009). The Healthy Lifestyle Change Program: A Pilot of a Community-Based Health Promotion Intervention for Adults with Developmental Disabilities, *American Journal of Preventive Medicine*, 37(6, S1), s201-S208.  
[dx.doi.org.wam.city.ac.uk/10.1016/j.amepre.2009.08.005](http://dx.doi.org.wam.city.ac.uk/10.1016/j.amepre.2009.08.005). Retrieved from <http://0-www.sciencedirect.com.wam.city.ac.uk/science/article/pii/S0749379709005194>
- Bergström, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities-a qualitative study. *Health Education Research*, 29(2), 259-271.
- Bergström, H., Hagströmer, M., Hogberg, J., & Elinder, L. S. (2013). A multi-component universal intervention to improve diet and physical activity among adults with

- intellectual disabilities in community residences: A cluster randomised controlled trial. *Research in Developmental Disabilities*, 34(11), 3847-3857.
- Bhaumik, S., Watson, J. M., Thorp, C. F., Tyrer, F., & McGrother, C. W. (2008). Body mass index in adults with intellectual disability: Distribution, associations and service implications: A population-based prevalence study. *Journal of Intellectual Disability Research*, 52(4), 287-298.
- Bodde, A. E., Seo, D. C., Frey, G. C., Lohrmann, D. K. & Van Puymbroeck, M. (2011). Developing a physical activity curriculum for adults with intellectual disabilities, *Health Promotion Practice*, 13(1), 116-123.
- Böhmer, C. J. M., Klinkenberg-Knol, E. C., & Niezen-de Boer, M. C. (2002). Prevalence, diagnosis and treatment of gastro-oesophageal reflux disease in institutionalised persons with an intellectual disability. *Journal of Intellectual & Developmental Disability*, 27(2), 92-105.
- Böhmer, C. J. M., Taminiau, J. A. J. M., Klinkenberg-Knol, E. C., & Meuwissen, S. G. M. (2001). The prevalence of constipation in institutionalized people with intellectual disability. *Journal of Intellectual Disability Research*, 45(3), 212-218.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Cane, J., O'Connor, D., & Michie, S. (2012). Validation of the Theoretical Domains Framework for use in behaviour change and implementation research. *Implementation Science*, 7(1), 37.
- Cartwright, L., Reid, M., Hammersley, R., Blackburn, C. & Glover, L. (2015). Food choice by people with intellectual disabilities at day centres: a qualitative study, *Journal of Intellectual Disabilities*, 19(2), 103-115.
- Cartwright, L., Reid, M., Hammersley, R., & Walley, R. M. (2017). Barriers to increasing the physical activity of people with intellectual disabilities. *British Journal of Learning Disabilities*, 45(1), 47-55. 10.1111/bld.12175.

- Caton, S., Chadwick, D., Chapman, M., Turnbull, S., Mitchell, D., & Stansfield, J. (2012). Healthy lifestyles for adults with intellectual disability: Knowledge, barriers, and facilitators. *Journal of Intellectual & Developmental Disability, 37*(3), 248-259.
- Chow, B. C., Huang, W. Y. J., Choi, P. H. N. & Pan, C. (2016). Design and methods of a multi-component physical activity program for adults with intellectual disabilities living in group homes, *Journal of Exercise Science & Fitness, 14*(1), 35-40.
- Conner, M., & Norman, P. (2015). *Predicting and changing health behaviour: Research and practice with social cognition models* (Third ed.). Maidenhead: Open University Press.
- Cooper, S., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: Population-based cross-sectional analysis. *BMC Family Practice, 16*(1), 1-11.
- Dairo, Y. M., Collett, J., Dawes, H., & Oskrochi, G. R. (2016). Physical activity levels in adults with intellectual disabilities: A systematic review, *Preventive Medicine Reports, 4*, 209-219. [dx.doi.org/10.1016/j.pmedr.2016.06.008](http://dx.doi.org/10.1016/j.pmedr.2016.06.008). Retrieved from <http://www.sciencedirect.com/wam.city.ac.uk/science/article/pii/S2211335516300584>
- de Ridder, D., Kroese, F., Evers, C., Adriaanse, M., & Gillebaart, M. (2017). Healthy diet: Health impact, prevalence, correlates, and interventions. *Psychology & Health, 32*(8), 907.
- de Winter, C. F., Bastiaanse, L. P., Hilgenkamp, T. I. M., Evenhuis, H. M., & Echteld, M. A. (2012). Cardiovascular risk factors (diabetes, hypertension, hypercholesterolemia and metabolic syndrome) in older people with intellectual disability: Results of the HA-ID study, *Research in Developmental Disabilities, 33*(6), 1722-1731.
- Deci, E. L., & Ryan, R. M. (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry, 11*(4), 227-268.
- Dixon-Ibarra, A., Driver, S., Vanderbom, K., & Humphries, K. (2017). Understanding physical activity in the group home setting: A qualitative inquiry. *Disability and Rehabilitation, 39*(7), 653-662.

- Dunkley, A. J., Tyrer, F., Doherty, Y., Martin-Stacey, L., Patel, N., Spong, R. et al. (2017). On behalf of the STOP diabetes team; development of a multi-component lifestyle intervention for preventing Type 2 diabetes and cardiovascular risk factors in adults with intellectual disabilities. *Journal of Public Health*, 1-10.
- Dunkley, A. J., Tyrer, F., Gray, L. J., Bhaumik, S., Spong, R., Chudasama, Y. et al. (2017). Type 2 diabetes and glucose intolerance in a population with intellectual disabilities: The STOP diabetes cross-sectional screening study. *Journal of Intellectual Disability Research*, 61(7), 668-681.
- Elliot, A. J., & McGregor, H. A. (2001). A 2 2 achievement goal framework. *Journal of Personality and Social Psychology*, 80(3), 501-519.
- Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2016). The physical health of British adults with intellectual disability: Cross sectional study. *International Journal for Equity in Health*, 15, 11.
- Goodwin, R. D. (2003). Association between physical activity and mental disorders among adults in the United States, *Preventive Medicine*, 36(6), 698-703.
- Hagger, M. S., & Chatzisarantis, N. L. D. (2015). Self-determination theory. In Conner, M., & Norman, P. (Eds.), *Predicting and changing health behaviour: research and practice with social cognition models* (Third ed.). Maidenhead: Open University Press.
- Hanna, L. M., Taggart, L., & Cousins, W. (2011). Cancer prevention and health promotion for people with intellectual disabilities: An exploratory study of staff knowledge. *Journal of Intellectual Disability Research*, 55(3), 281-291.
- Harrington, D. M., Edwardson, C. L., Henson, J., Khunti, K., Yates, T., & Davies, M. J. (2016). Moderate to vigorous physical activity, not sedentary time, is associated with total and regional adiposity in a sample of UK adults at risk of Type 2 diabetes. *Physiological Measurement*, 37(10), 1862.

- Hiles, S. A., Lamers, F., Milaneschi, Y., & Penninx, B. W. J. H. (2017). Sit, step, sweat: Longitudinal associations between physical activity patterns, anxiety and depression. *Psychological Medicine, 47*(8), 1466-1477.
- Hler, F., Thome, J., & Reis, O. (2015). Polypharmacy in the treatment of subjects with intellectual disability. *Journal of Neural Transmission, 122*(S1), S100.
- Hosking, F. J., Carey, I. M., Shah, S. M., Harris, T., DeWilde, S., Beighton, C., et al. (2016). Mortality among adults with intellectual disability in England: Comparisons with the general population. *American Journal of Public Health, 106*(8), 1483-1490.
- Hsieh, K., Rimmer, J. H., & Heller, T. (2014). Obesity and associated factors in adults with intellectual disability. *Journal of Intellectual Disability Research, 58*(9), 851-863.
- Jakes, R. W., Day, N. E., Khaw, K. T., Luben, R., Oakes, S., Welch, A. et al. (2003). Television viewing and low participation in vigorous recreation are independently associated with obesity and markers of cardiovascular disease risk: EPIC-Norfolk population-based study. *European Journal of Clinical Nutrition, 57*(9), 1089.
- Koritsas, S., & Iacono, T. (2016). Weight, nutrition, food choice, and physical activity in adults with intellectual disability. *Journal of Intellectual Disability Research, 60*(4), 355-364. 10.1111/jir.12254
- Krahn, G. L., & Fox, M. H. (2014). Health disparities of adults with intellectual disabilities: What do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities, 27*(5), 431-446.

- Ku, P., Fox, K. R., & Chen, L. (2016). Leisure-time physical activity, sedentary behaviors and subjective well-being in older adults: An eight-year longitudinal research. *Social Indicators Research, 127*(3), 1349-1361.
- Kubo, A., Block, G., Quesenberry Jr, C.,P., Buffler, P., Corley, D. A., & Quesenberry, C. P. J. (2014). Dietary guideline adherence for gastroesophageal reflux disease. *BMC Gastroenterology, 14*(1), 144.
- Kuijken, N. M. J., Naaldenberg, J., Nijhuis-van der Sanden, M.W., & van Schrojenstein-Lantman de Valk, H. M. J. (2016). Healthy living according to adults with intellectual disabilities: Towards tailoring health promotion initiatives. *Journal of Intellectual Disability Research, 60*(3), 228-241.
- Loprinzi, P. D. (2015). Dose–response association of moderate-to-vigorous physical activity with cardiovascular biomarkers and all-cause mortality: Considerations by individual sports, exercise and recreational physical activities. *Preventive Medicine, 81*, 73-77.
- Loprinzi, P. D., Addoh, O., & Mann, J. R. (2017). Association between muscle strengthening physical activities and mortality among American adults with mobility limitations. *Preventive Medicine, 99*, 207-210.
- Luomala, H. T., Hellén, K., & Jokitalo, M. (2018). Dieting, priming, food meanings and (un)healthy choices: When shoppers fall for pleasure, *Journal of retailing and consumer services, 41*, 305-311.
- Luszczynska, A., & Schwarzer, R. (2015). Social cognitive theory. In Conner, M. & Norman, P. (Eds.), *Predicting and changing health behaviour: Research and practice with social cognition models* (Third ed., pp. 225-251). Maidenhead: Open University Press.

- MacRae, S., Brown, M., Karatzias, T., Taggart, L., Truesdale-Kennedy, M., Walley, R. et al. (2015). Diabetes in people with intellectual disabilities: A systematic review of the literature, *Research in Developmental Disabilities*, 47, 352-374.
- Maddox, J. E., & Rogers, R. W. (1983). Protection motivation and self-efficacy: a revised theory of fear appeals and attitude-change. *Journal of Experimental Social Psychology*, 19(5), 469-479.
- Mahy, J., Shields, N., Taylor, N. F., & Dodd, K. J. (2010). Identifying facilitators and barriers to physical activity for adults with Down Syndrome. *Journal of Intellectual Disability Research*, 54(9), 795-805.
- Johnston, M., Dixon, D., Hart, J., Glidewell, L., Carin, S. & Pollard, B. (2014). Discriminant content validity: A quantitative methodology for assessing content of theory-based measures, with illustrative applications. *British Journal of Health Psychology*, 19(2), 240-257.
- Marks, B., Sisirak, J., & Chang, Y. (2013). Efficacy of the HealthMatters program train-the-trainer model. *Journal of Applied Research in Intellectual Disabilities*, 26(4), 319-334.
- Marshall, D., McConkey, R., & Moore, G. (2003). Obesity in people with intellectual disabilities: The impact of nurse-led health screenings and health promotion activities. *Journal of Advanced Nursing*, 41(2), 147-153.
- Matthews, L., Mitchell, F., Stalker, K., McConnachie, A., Murray, H., Melling, C. et al. (2016). Process evaluation of the walk well study: A cluster-randomised controlled trial of a community based walking programme for adults with intellectual disabilities. *BMC Public Health*, 16, 527.ö
- McDermott, S., Whitner, W., Thomas-Koger, M., Mann, J. R., Clarkson, J., Barnes, T. L. et al. (2012). An efficacy trial of 'steps to your health', a health promotion programme for adults with intellectual disability. *Health Education Journal*, 71(3), 278-290.

- McGuire, B. E., Daly, P., & Smyth, F. (2007). Lifestyle and health behaviours of adults with an intellectual disability. *Journal of Intellectual Disability Research, 51*(7), 497-510.
- Melville, C. A., Boyle, S., Miller, S., Macmillan, S., Penpraze, V., Pert, C. et al. (2011). An open study of the effectiveness of a multi-component weight-loss intervention for adults with intellectual disabilities and obesity. *British Journal of Nutrition, 105*(10), 1553-1562.
- Melville, C. A., Hamilton, S., Miller, S., Boyle, S., Robinson, N., Pert, C., & Hankey, C. R. (2009). Carer knowledge and perceptions of healthy lifestyles for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 22*(3), 298-306.
- Melville, C. A., Oppewal, A., öäfer Elinder, L., Freiburger, E., Guerra-Balic, M., Hilgenkamp, T. I. M., et al. (2017). Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities: A systematic review. *Preventive Medicine, 97*, 62-71.
- Messent, P. R., Cooke, C. B., & Long, J. (1998). Daily physical activity in adults with mild and moderate learning disabilities: Is there enough? *Disability and Rehabilitation, 20*(11), 424-427.
- Mikulovic, J., Vanhelst, J., Salleron, J., Marcellini, A., Compte, R., Fardy, P. S., & Bui-Xuan, G. (2014). Overweight in intellectually-disabled population: Physical, behavioral and psychological characteristics, *Research in Developmental Disabilities, 35*(1), 153-161.
- Ogden, J. (2007). *Health psychology: A textbook* (4th ed.). Maidenhead: Open University Press McGraw-Hill Education.
- Onvani, S., Haghghatdoost, F., Surkan, P. J., Larijani, B., & Azadbakht, L. (2017). Adherence to the healthy eating index and alternative healthy eating index dietary patterns and mortality from all causes, cardiovascular disease and cancer: A meta-analysis of observational studies. *Journal of Human Nutrition and Dietetics, 30*(2), 216-226.

- Orenstein, L., Chetrit, A., & Dankner, R. (2016). Healthy lifestyle pattern is protective against 30-yr cancer incidence in men and women: A cohort study. *Nutrition and Cancer, 68*(3), 410-419.
- Owen, N., Leslie, E., Salmon, J., & Fotheringham, M. (2000). Environmental determinants of physical activity and sedentary behavior. *Exercise & Sport Science Reviews, 28*(4), 153.
- Pelletier, J.E., & Joussemet, M. (2017). The benefits of supporting the autonomy of individuals with mild intellectual disabilities: An experimental study. *Journal of Applied Research in Intellectual Disabilities, 30*(5), 830-846.
- Perez-Cruzado, D., & Cuesta-Vargas, A. I. (2016). Changes on quality of life, self-efficacy and social support for activities and physical fitness in people with intellectual disabilities through multimodal intervention. *European Journal of Special Needs Education, 31*(4), 553-564.
- Proper, K. I., Singh, A. S., van Mechelen, W., & Chinapaw, M. J. M. (2011). Sedentary behaviors and health outcomes among adults: a systematic review of prospective studies, *American Journal of Preventive Medicine, 40*(2), 174-182.
- Ptomey, L. T., Gibson, C. A., Lee, J., Sullivan, D. K., Washburn, R. A., Gorczyca, A. M., et al. (2017). Caregivers' effect on weight management in adults with intellectual and developmental disabilities, *Disability and Health Journal, 10*(4), 542-547.
- Rahe, C., Unrath, M., & Berger, K. (2014). Dietary patterns and the risk of depression in adults: A systematic review of observational studies. *European Journal of Nutrition, 53*(4), 997-1013.

- Robertson, J., Hatton, C., Emerson, E., & Baines, S. (2014). The impact of health checks for people with intellectual disabilities: An updated systematic review of evidence. *Research in Developmental Disabilities, 35*(10), 2450-2462.
- Rodgers, J. (1998). 'Whatever's on her plate': Food in the lives of people with learning disabilities. *British Journal of Learning Disabilities, 26*(1), 13-16.
- Rogers, R. W. (1975). A protection motivation theory of fear appeals and attitude change. *Journal of Psychology, 91*(1), 93.
- Ruud, M. P., Raanaas, R. K., & Bjelland, M. (2016). Caregivers' perception of factors associated with a healthy diet among people with intellectual disability living in community residences: A concept mapping method. *Research in Developmental Disabilities, 59*, 202-210.
- Sedentary Behaviour, R. N. (2012). Letter to the editor: Standardized use of the terms 'sedentary' and 'sedentary behaviours'. *Applied Physiology, Nutrition & Metabolism, 37*(3), 540-542.
- Sigstad, H. M. H. (2014). Characteristic interviews, different strategies: methodological challenges in qualitative interviewing among respondents with mild intellectual disabilities. *Journal of Intellectual Disabilities, 18*(2), 188-202.
- Smyth, C. M., & Bell, D. (2006). From biscuits to boyfriends: The ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities, 34*(4), 227-236.
- Spanos, D., Hankey, C. R., Boyle, S., Koshy, P., Macmillan, S., Matthews, L., et al. (2013). Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: A qualitative study. *Journal of Intellectual Disability Research, 57*(1), 90-102.
- Spanos, D., Hankey, C. R., & Melville, C. A. (2016). The effectiveness of a weight maintenance intervention for adults with intellectual disabilities and obesity: A single stranded study. *Journal of Applied Research in Intellectual Disabilities, 29*(4), 317-329.

- Stancliffe, R. J., & Anderson, L. L. (2017). Factors associated with meeting physical activity guidelines by adults with intellectual and developmental disabilities. *Research in Developmental Disabilities, 62*, 1-14.
- Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Bershinsky, J., Taub, S., et al. (2011). Overweight and obesity among adults with intellectual disabilities who use intellectual disability/developmental disability services in 20 U.S. States. *American Journal on Intellectual and Developmental Disabilities, 116*(6), 401-418.
- Thorp, A. A., Owen, N., Neuhaus, M., & Dunstan, D. W. (2011). Sedentary behaviors and subsequent health outcomes in adults: a systematic review of longitudinal studies 1996-2011. *American Journal of Preventive Medicine, 41*(2), 207-215.
- Tremblay, M. S., Colley, R. C., Saunders, T. J., Healy, G. N., & Owen, N. (2010). Physiological and health implications of a sedentary lifestyle. *Applied Physiology, Nutrition & Metabolism, 35*(6), 725-740.
- Trip, H., Conder, J., Hale, L., & Whitehead, L. (2016). The role of key workers in supporting people with intellectual disability in the self-management of their diabetes: A qualitative New Zealand study. *Health & Social Care in the Community, 24*(6), 789-798.
- Tsai, A. C., Hsu, H., & Chang, T. (2011). The mini nutritional assessment (MNA) is useful for assessing the risk of malnutrition in adults with intellectual disabilities. *Journal of Clinical Nursing, 20*(23), 3295-3303.
- Tudor-Locke, C., & Myers, A. M. (2001). Challenges and opportunities for measuring physical activity in sedentary adults. *Sports Medicine, 31*(2), 91-100.
- Tyrer, F., Dunkley, A. J., Spong, R., Gangadharan, S. K., Bhaumik, S., & Khunti, K. (2017). Involving service users with intellectual disability in research: Experiences from the STOP diabetes study. *Journal of Policy and Practice in Intellectual Disabilities, 14*(3), 255-261.
- U.S. Department of Health and Human Services. (2008). *Physical activity guidelines for Americans*. Retrieved from <https://health.gov/paguidelines/>

- Umpierre, D., Ribeiro, P. A. B., Kramer, C. K., Leitao, C. B., Zucatti, A. T. N., Azevedo, M. J., et al. (2011). Physical activity advice only or structured exercise training and association with HbA(1c) levels in Type 2 diabetes A systematic review and meta-analysis. *Journal of the American Medical Association*, *305*(17), 1790-1799.
- van Schijndel-Speet, M., Evenhuis, H. M., van Wijck, R., van Montfort, K. C. A. G. M., & Echteld, M. A. (2017). A structured physical activity and fitness programme for older adults with intellectual disabilities: Results of a cluster-randomised clinical trial. *Journal of Intellectual Disability Research*, *61*(1), 16-29.
- van Schijndel-Speet, M., Evenhuis, H. M., van Wijck, R., van Empelen, P., & Echteld, M. A. (2014). Facilitators and barriers to physical activity as perceived by older adults with intellectual disability. *Intellectual and Developmental Disabilities*, *52*(3), 175-186.
- Wallace, R. A. (2007). Clinical audit of gastrointestinal conditions occurring among adults with down syndrome attending a specialist clinic. *Journal of Intellectual & Developmental Disability*, *32*(1), 45-50.
- Willems, M., Hilgenkamp, T. I. M., Havik, E., Waninge, A., & Melville, C. A. (2017). Use of behaviour change techniques in lifestyle change interventions for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, *60*, 256-268.
- Willett, W. C. (1994). Diet and health: What should we eat? *Science*, *264*(5158), 532-537.
- Wilmot, E. G., Edwardson, C. L., Achana, F. A., Davies, M. J., Gorely, T., Gray, L. J., et al. (2012). Sedentary time in adults and the association with diabetes, cardiovascular disease and death: Systematic review and meta-analysis. *Diabetologia*, *55*(11), 2895-2905.
- Wirt, A., & Collins, C. E. (2009). Diet quality: what is it and does it matter? *Public Health Nutrition*, *12*(12), 2473-2492.
- Yates, T., Khunti, K., Troughton, J., & Davies, M. (2009). The role of physical activity in the management of Type 2 Diabetes Mellitus. *Postgraduate Medical Journal*, *85*(1001), 129-133.

Yates, T., Davies, M., & Khunti, K. (2013). Prevention of Type 2 diabetes: The role of physical activity in Schwartz, P. & Reddy, P. (Eds.). *Prevention of Diabetes* (pp. 159-176). John Wiley & Sons: UK.

Young, A. F., & Chesson, R. A. (2008). Determining research questions on health risks by people with learning disabilities, carers and care-workers. *British Journal of Learning Disabilities*, 36(1), 22-31.

## Appendix A: Interview guide

### Interview schedule-Carers

#### *Healthy eating*

- 1) What is healthy eating? (*how would you go about it? Examples of healthy food and drink? Preparation? What is important for a healthy diet?*)
- 2) What is unhealthy eating? (*examples of food/drink/preparation methods? Key elements?*)

#### Knowledge

**For the following questions, it is fine to use your experiences as a carer to guide your answers, but please stick to generalities and do not reveal intimate personal information about your client(s)/family member. (Let us know if it is hard to give information without doing that, as there are alternative questions I can ask to make it easier)**

- 3) For what reasons might an adult with a (mild-moderate) learning disability want (or need?) to consider eating a healthier diet? (*your service users/family member?*)

#### Outcome expectancies

- 4) What can help them to achieve this?

#### Facilitators

- 5) How about the role of social support? (*from carers? Peers? Others – anyone else?*)

#### Positive social support

- 6) What may hinder this? (*get in the way/make it harder or more difficult?*)

#### Barriers

- 7) What about the influence of others? In what ways can that make it harder?

#### Negative social support

- 8) What might make, in your experience, a service user/family member more confident they can move to/maintain a healthier diet? (*particularly in the face of obstacles – e.g. low mood, when they're busy, at a social event*)
- 9) What can help you/other people who support a person/persons with learning disabilities feel more confident to help them have/maintain a healthy diet? (*in the face of other obstacles such as competing demands, time constraints, challenging behaviour, considerations of choice*)

#### Self-efficacy (proxy for adult with learning disabilities, and for carers)

- 10) Have any of your clients/has your family member ever decided to try to eat more healthily? (*when you were involved in their support?*)

#### Past behaviour

- 11) If so, did you ever try setting goals?
- 12) What can be helpful when goal setting?
- 13) What are the difficulties? The limitations?
  - a. What about goal type (specificity)?
  - b. Goal proximity? (*give examples if needed*)
    - i. Any considerations to bear in mind?

#### Goal setting (proximal/distal)

- 14) Do any of your service users/does your family member want to have a healthier diet now?

#### Proxy intention

- 15) Is that something you see as a priority for them? (*what about competing demands? – stick to generalities. E.g. being more independent, managing stress, managing other health concerns, having fun and enjoyment, getting enough basic support, managing finances*)

#### Intention to support, competing goals/intentions

16) Is that something you think others involved in supporting this person want?

#### Others intentions

#### *Physical activity*

(Same questions as for healthy eating)

#### *Sedentary behaviour*

- 1) What is sedentary behaviour?
- 2) How would a person decrease their sedentary behaviour?

#### Knowledge

## Appendix B: Vignettes for adults with learning disabilities

*Scenario questions (questions that tap into different constructs that using diet and physical activity specific questions – do not have to use all questions but try to tap into all those different constructs, depending on context and responsiveness of participants, so they do not become over-burdened or reveal too much information about their carer/service user as appropriate.*

### Diet:

#### Scenario 1:

Jack is 26. He has a mild learning disability.

He lives on his own.

He wants to eat more fruit because it is good for him.

He is not sure he can do it.

What can help him be more sure? (beliefs about capability – self-efficacy)

*Prompts:*

Where do you go to find out about different types of fruit? (acquiring knowledge, social support)

Where do you go to buy fruit? (support, do this alone or with someone?) (knowledge, social support)

Who do you talk to if you want help to buy fruit? (social support)

#### Scenario 2:

Jack (from box 1) has planned to eat 2 pieces of fruit to eat today, but he is feeling a bit low. It is an important goal to him. What can he do to help make that plan happen anyway? (self-efficacy)

#### Scenario 3:

Jane has a support worker who helps her with a few activities in her everyday life. She has a learning disability but is fairly independent. They have a review meeting. Jane tells her support worker she wants to eat more vegetables so she can be more healthy.

They sit down together talk about how Jane can do this. Her support worker suggests that they set some goals together.

Pretend you're Jane. What goals would you set? What can make it more easy? (prompts, small targets, options?) (goal setting – proximal, distal)

They agree to check how Jane is getting on. If you were Jane, how would you do it? (prompt – weekly food diary? Next review – in 3 months? Same as one term at college. What can make former/latter better?) (self-monitoring, frequency)

Scenario 4:

Asim is 38. He has a busy day at College on Fridays. He takes a class in the morning and a class in the afternoon. What can he do to make sure he has a healthy meal at lunchtime? (self-efficacy)

What can make a healthy meal? (knowledge)

What can make someone want to eat more healthy foods? (outcome expectancies)

Scenario 5:

Tracey has a friend that does not like fruit and thinks they should have tea and a biscuit instead as a snack. What can Tracey do to stick to her goal of eating more fruit? (self-efficacy)

## Physical activity:

### Scenario 1:

Syrah has a moderate learning disability and lives in a shared home with other people who have learning disabilities. Her doctor says that she needs to do more exercise. What exercise can people do? (knowledge)

Where would you go to find out more about different types of exercise? (knowledge, social support)

Where can people do exercise? (knowledge)

Who can Syrah go to if she wants help to do more exercise? (social support)

What can Syrah do to make sure she does more exercise? (planning, goal-setting)

### Scenario 2:

Syrah has decided she would like to go for walks, but she is feeling a bit lazy today. What can she do or say to help herself get some exercise today? (self-efficacy)

What can Syrah get out of doing some exercise? (outcome expectancy)

What can make it more easy for her to do exercise? (facilitators)

What can make it more hard? (barriers)

### Scenario 3:

Mo lives with his family. He likes watching TV at home. But he wants to be more active and loves to dance. He also wants to do it to be more healthy. There is a dance class at his local college.

Mo is close to his sister. She wants to help him. What can she do to make it more easy for him to go to dance class instead of staying at home and watching TV? (social support)

How can his family help him stick to it? (social support)

### Scenario 4:

Magda is 34. She uses a wheelchair. She tried out wheelchair basketball at a Disability sports day and loved it.

Magda lives with her family. How can they help her go to wheelchair basketball? (social support, facilitators)

What about if she is in a bad mood? (social support)

Or if she has a busy week (but it does not clash with the basketball sessions)? (planning)

Magda has two parents that are very supportive. Her little sister, however, teases her about going to wheelchair basketball. It can make her feel a bit nervous and unsure. What can help her feel more confident about it? (self-efficacy)

## Appendix C: Coding Framework

<b>Construct</b>	<b>Definition</b>	<b>Examples</b>	<b>Notes</b>
Outcome expectancies	An expected outcome of a course of action or behaviour (e.g. diet/activity change)	Enjoyment, pleasure, comfort; Social reinforcement, inclusion, employment opportunities, status, responsibility	Concerns about ability to perform behaviour are coded under self-efficacy (e.g. fear of failure = mastery/performance avoidance) but expectations of consequences of that (e.g. social acceptance) are outcome expectancies
Self-efficacy	A realistic self-appraisal of ability to carry out behaviour in the face of obstacles/difficulties; to a certain standard; impacted by mastery, vicarious learning/observing role models	Increasing knowledge, skills, abilities and applying these (mastery), observing others' behaviour to imitate/copy (vicarious learning/role models)	Role modelling for others BUT unclear if operates through mastery as has performative element which can distort self-appraisal Self-efficacy of adults with learning disabilities distinguished from self-efficacy of carers. Self-efficacy of carers also applied to addressing challenging behaviour which may arise when promoting healthier lifestyles/behaviour change
Proxy efficacy	An appraisal of another persons' ability to carry out tasks/behaviours for you (i.e. on your behalf)	Carers deciding what is healthy/not through gathering knowledge (what is healthy, managing budgets, availability) as an adult with ID may struggle with this	Applies to adults with learning disabilities in this context due to their cognitive and physical vulnerabilities – looking at what may help them develop this sense of proxy efficacy in carers
Social support	Positive and negative social support which impacts diet and activities of adults with learning disabilities, includes peers, paid and unpaid carers	Encouraging healthier behaviour; peer pressure; facilitators and barriers to effective collaboration between people in supporting roles; exploitation	Practical and emotional support are distinct. Overlap between carer role modelling healthy/unhealthy behaviour and providing positive/negative social support, so latter coded by active encouragement or not (emotional), communication strategies

			(emotional), support given to access opportunities (practical)
Goal setting	Proximal (short term) and distal (long term) goals set to achieve changes in behaviour and desired outcomes	Goals set in annual person-centred reviews (target) – distal; aiming to e.g. eat two more pieces of fruit each week – proximal; aiming to cook a new meal may be distal as it takes time to learn; mastering a particular step may be proximal	Goals may be in gaining knowledge and skill development (achievement oriented) or outcome focussed (e.g. weight loss) Related to monitoring progress and outcomes but not the same
Monitoring behaviour	Monitoring progress attained over time: frequency and what to monitor are two separate but related elements	Gains in skills and knowledge of healthier living; monitoring weight; monitoring for desired outcomes in subjective well-being	May be focussed on degree of mastery/level of achievement; in relation to self (absolute mastery) or relative to others (performance mastery) or outcomes e.g. changes in wellbeing, weight, body image
Barriers and facilitators	Personal, social and environmental facilitators and barriers to behaviour change	Time, resources; opportunities; intrapersonal factors (e.g. openness to trying new foods and experiences, mental health); accessibility; bureaucratic processes; safety of local environment; stigma	Lot of overlap between social support offered, role modelling and barriers and facilitator
Other: Motivation, values	Drive or desire to take up healthier behaviours, important values (e.g. choice, duty of care)	Giving people options; noncoercion; duty to provide information and support	Choice: the right to self-determination by adults with learning disabilities. Duty of care – the obligation for carers to support them to meet their health and wellbeing need

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## SECTION C: PUBLICATIONS

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### **Integrating health psychology theory and research with health education and training for adults with learning disabilities in healthy eating, physical activity and sedentary behaviour**

Adults with mild-moderate learning disabilities tend to eat less healthily and engage in lower levels of physical activity and higher levels of sedentary behaviour than adults in the general population which contributes to higher levels of overweight, obesity and underweight in this cohort (Dunkley et al., 2017; Melville et al., 2017). This can be at least in part due to their greater independence in making choices in relation to diet and the activities they participate in (de Winter et al., 2012).

Yet a significant proportion of this group rely on the guidance and support of a carer for day to day activities to some extent and this can also involve shopping, cooking and other pursuits such as recreational physical activity in the local environment (Smyth & Bell, 2006). The support they receive can be crucial, yet carers can struggle between perceived moral dilemmas around enabling a person to make their own choices and providing duty of care to promote their health (Spanos et al., 2013). They may need training to increase their knowledge on healthy eating, cooking, physical activity and reducing sedentary behaviour. Additionally, adults with learning disabilities may need to increase their self-efficacy in trying out novel foods and activities particularly if they have co-occurring food sensitivities and physical impairments, (Bergström, Elinder, & Wihlman, 2014) and carers may need this to cope effectively with behaviour that may challenge when assisting with health promotion and behaviour change.

#### **Research in progress**

For these reasons social cognitive theory (Bandura, 2001) was chosen to underpin health promotion workshops for a group of adults with mild-moderate learning disabilities, and staff training in a social care context. These aim to increase knowledge and positive outcome

expectancies of both groups of participants, so they could provide peer support to each other. Teaching will be experiential for adults with learning disabilities as they may struggle with memory and understanding (e.g., Bergström et al., 2014; McDermott et al., 2012). We will use role plays to help adults with learning disabilities provide each other with positive emotional support. We plan to create easy read recipes and cooking videos with adults with learning disabilities and physical impairments as a knowledge resource and so they act as role models for their peers and staff to improve self-efficacy for both groups. Staff will also have workshops to explore nuances around informed decision making, exploring the roles of decision complexity, familiarity and working within tight resource constraints (Smyth & Bell, 2006), to support them to persuade clients to engage with these behaviours whilst respecting their right to self-determination. They will also be supported to reflect on their own role in enabling healthier choices within the relationship they have with their clients.

Adults with mild-moderate learning disabilities need support to eat healthily, be more active and reduce sedentary behaviour. A social cognitive theory-based approach to training could be useful with adults with learning disabilities and staff working with them. This work aims to improve knowledge, positive outcome expectancies, engender positive social support and create resources that enable adults with learning disabilities to improve self-efficacy for themselves and staff on cooking healthy dishes.

**Link to publication:**

Bains, K. K. (2017), Integrating health psychology theory and research with health education and training for adults with learning disabilities in healthy eating, physical activity and sedentary behaviour, *Journal of Health Psychology and Public Health*, 1(2). Last accessed on 30.04.17 from [www.hpphn.org.uk/275/Integrating-health-psychology-theory-and-research-with-health-education-and-training-for-adults-with-learning-disabilities-in-healthy-eating-physical-activity-and-sedentary-behaviour](http://www.hpphn.org.uk/275/Integrating-health-psychology-theory-and-research-with-health-education-and-training-for-adults-with-learning-disabilities-in-healthy-eating-physical-activity-and-sedentary-behaviour)

## References

- Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, 52(1), 1-26. doi:10.1146/annurev.psych.52.1.1
- Bergström, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities-a qualitative study. *Health Education Research*, 29(2), 259-271. doi:10.1093/her/cyt111
- de Winter, C. F., Bastiaanse, L. P., Hilgenkamp, T. I. M., Evenhuis, H. M., & Echteld, M. A. (2012). Cardiovascular risk factors (diabetes, hypertension, hypercholesterolemia and metabolic syndrome) in older people with intellectual disability: Results of the HA-ID study. *Research in Developmental Disabilities*, 33(6), 1722-1731.
- Dunkley, A. J., Tyrer, F., Gray, L. J., Bhaumik, S., Spong, R., Chudasama, Y. et al. (2017). Type 2 diabetes and glucose intolerance in a population with intellectual disabilities: The STOP diabetes cross-sectional screening study. *Journal of Intellectual Disability Research*, 61(7), 668-681. doi:10.1111/jir.12380
- McDermott, S., Whitner, W., Thomas-Koger, M., Mann, J. R., Clarkson, J., Barnes, T. L. et al. (2012). An efficacy trial of 'steps to your health', a health promotion programme for adults with intellectual disability. *Health Education Journal*, 71(3), 278-290. doi:10.1177/0017896912441240
- Melville, C. A., Oppewal, A., Elinder, L. S., Freiburger, E., Guerra-Balic, M., Hilgenkamp, T. I. M. et al. (2017). Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities - A systematic review. *Preventive Medicine*, 97, 62-71. doi:10.1016/j.ypmed.2016.12.052
- Smyth, C. M., & Bell, D. (2006). From biscuits to boyfriends: The ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*, 34(4), 227-236. doi:10.1111/j.1468-3156.2006.00402.x

Spanos, D., Hankey, C. R., Boyle, S., Koshy, P., Macmillan, S., Matthews, L. et al. (2013). Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: A qualitative study. *Journal of Intellectual Disability Research*, 57(1), 90-102. doi:10.1111/j.1365-2788.2011.01530.x

# Finding a suitable placement for entry into a Professional Doctorate or Stage 2 Training equivalent

## Summary

Undertaking a professional doctorate or Stage 2 independent training equivalent provided by the British Psychological Society enables training as an applied psychologist, using evidence-based practice to provide services to the public. Securing a work placement is one of the most important pre-requisites for successful application to entry to some courses, including those specialising in health, occupational and sport and exercise psychology. This article will discuss key elements to consider when aiming to find a placement, including role and trainee contribution, organisational support, training and development opportunities, inter-professional collaboration and funding to appraise suitability for placement.

## Introduction

Psychology postgraduates that aim to become applied psychologists need to undertake specialist training in their field of interest. Currently these include clinical, counselling, health, educational, forensic, occupational and sport and exercise psychology. This article will focus on the importance of finding a suitable placement for those aiming to become applied health, sport and exercise or occupational psychologists (see Figure 1). This is because there is considerable overlap in the qualification process for these fields and candidates need to independently secure a placement to enter further training, which can potentially be the only one they have throughout their training. This may contrast with other trainee courses, such as counselling psychology, where placements are short-term, focussed on developing skills in using specific therapeutic approaches to help specific client groups and may be sourced with the assistance of a placement support officer.

Figure 1. The fields of health, occupational and sport & exercise psychology

**Health Psychology:** Focusses on people's experiences of health and illness, including health promotion, chronic illness management and interactions with the healthcare system.

**Occupational Psychology:** Focusses on performances of people at work, how individuals, groups and organisations function, including looking at how to improve organisational effectiveness and job satisfaction.

**Sport & Exercise Psychology:** Use of psychology theory, research and techniques to help athletes perform optimally and increase uptake of exercise in the general public.

(BPS Careers, 2018; See <https://www.bps.org.uk/become-psychologist/additional-careers-resources> for more information)

## The process

Undertaking a Masters is the first stage to obtaining a professional doctorate and entering a professional practice. This stage helps develop a theoretical knowledge of your chosen subject. The professional doctorate, or independent stage two training equivalent, involves application of theoretical knowledge gained through stage 1 training to research and applied practice with specific client groups in the field. This is in contrast to a PhD, which enables qualification as a research psychologist (see Table 1).

**Table 1**  
*Qualification process: applied versus research psychology*

	<b>Qualification</b>		
	<b>Professional Doctorate</b>	<b>Stage 2</b>	<b>PhD</b>
<i>Awarded by</i>	University (accredited by BPS)	British Psychological Society (BPS)	University
<i>Emphasis</i>	Applied practice	Applied Practice	Research
<i>Placement</i>	Yes	Yes (but see below)	No
<i>Optional combinations and fees and funding</i>	Most courses are self-funded and incur £6000-6500 a year in fees for full time study.	May be carried out concurrently with PhD and incur additional fees but can reduce pressure to find an appropriate professional placement as some activities fulfil both (e.g. conducting an intervention as a research study ticks both boxes).	May be carried out concurrently with Stage 2 training and a few courses integrate the two, providing funding to cover fees of both plus some living expenses.
<i>Dominant career focus</i>	Psychological intervention and assessment planning, delivery and evaluation with target client groups and other professionals working with them.	Psychological intervention planning, delivery and evaluation with target client groups and other professionals working with them.	Psychological research into various fields of psychology (e.g. cognition, affect, theory, intervention development).
<i>Typical length (full time)</i>	2 years (minimum) supervised practice by a practitioner psychologist	2 years (minimum) supervised practice by practitioner psychologist	3 years

## **The placement**

Trainees acquire a significant amount of their knowledge and skills in research and practice on placement. Thus, it is essential trainees are able to secure a role that will enable them to develop this. They will also need to demonstrate, when applying for course entry, how they plan to meet at least some of their competences in this context. Competences are listed in detail in candidate handbooks on the BPS website (see <https://www.bps.org.uk/psychologists/society-qualifications/>). Indeed, finding a suitable placement can be the most significant barrier to entry for prospective candidates as they may struggle to identify or create opportunities to do this. However, it is accepted prospective trainees may not know how to address all aspects of their portfolio at the outset of their training. Novel opportunities may also arise during their studies and organisational changes may occur in that time. Candidates may also sometimes change their placements during training, though this is not mandatory and depends on individual circumstances.

Nevertheless, some competencies may take longer to fulfil than others and it may help prospective trainees to contact a potential supervisor or course director to ascertain which ones these are likely to be. For example, a research project may take time to plan and conduct, and trainees will need to allow time for ethics applications and consider how they plan to access participants in a professional context. This is particularly the case for vulnerable groups (e.g. young people, adults using care services) or certain contexts (e.g. the NHS).

## **Guidance and Resources**

Prospective candidates may also receive some guidance about potential settings for placement depending on their interests by contacting course tutors of institutions offering training at masters or doctoral level. Additionally, attending conferences and local network events in their specialist field may help them find out where current trainees are based or where to apply for appropriate roles that can form the basis of training (see also table 2). Further information can also be gathered from BPS Careers (<https://careers.bps.org.uk/>) or Prospects ([www.prospects.ac.uk](http://www.prospects.ac.uk)). BPS Member Divisions in health, occupational and sport and exercise psychology can also be followed on Twitter. They have links to prominent psychologists, and also advertise appropriate roles for placement and host academic conferences in their fields.

**Table 2****Placement settings and roles for Health Psychology, Sport and Exercise Psychology and Occupational Psychology**

	<b>Health</b>	<b>Field Sport and Exercise</b>	<b>Occupational</b>
<i>Settings</i>	Universities, hospitals, Private Sector, Third Sector	Sports clubs, athletics programmes, health sector, occupational sector	Human Resources, Business, NHS, Government, Prison Service, Ministry of Justice
<i>Example roles</i>	Research assistant, assistant psychologist, recovery worker, mental health support worker	Sports Coach, PE teacher, exercise or fitness instructor, health promotion	HR, Recruitment, Management, Administrative/Office-based roles

**Things to consider when choosing a placement**

It is important for candidates to consider which client groups they aim to work with and topics they wish to specialise in within their field and organisational context. Training within large or specialist organisations such as the NHS will likely mean that their role will be structured as candidates will have pre-specified responsibilities, such as within the Improving Access to Psychological Therapies (IAPT) programme or research roles. Training within smaller organisations, including some charities, sports clubs or business enterprises, can lead to a more varied role and potentially greater flexibility. However, there may be less understanding of the skillset and knowledge of a trainee psychologist, their potential contribution to their workplace and potentially less contact with other trainees in the field.

**Funding**

Having a paid role on placement can facilitate access to training and continuing professional development opportunities, but trainees may need to independently conduct extra projects to fulfil some of their competences outside of their working hours. This is in addition to time

spent writing reports where this is not part of their normal role, thus increasing workload. Having a research role, for example, may facilitate development of a research study and conducting a systematic review. However, trainees may need to seek out other opportunities to develop as practitioners, such as conducting assessments or working directly with clients. Due to greater potential flexibility of unpaid roles, candidates may be able to achieve more of their training goals during their daily role, but potential trainees may also need to consider how training will be funded and how living expenses will be met. This is because most trainees rely on income from employment or personal sources rather than a grant or stipend.

### **Ethics**

Candidates in non-traditional roles may need to be more proactive in understanding what is needed to conduct ethical professional practice in accordance with professional bodies such as the BPS and the Healthcare Professions Council (HCPC) as these may not always align with organisational policy. To err on the side of caution, best practice may be to follow whichever guidelines are most stringent. Trainees should gain advice from their supervisors once they begin their training, but it is help to be mindful of this when applying for course entry.

### **Considering organisational impact**

Planning involves some understanding of how competences may be achieved whilst on placement and it also helps to map out anticipated impact on clients and potentially, the wider organisation. Within my training, for example, this manifested in thinking about how research undertaken could impact on the development and delivery of health promotion interventions to service users with learning disabilities. This also involved anticipating training needs of allied professionals, including how to improve their knowledge and skills in providing support to increase clients' uptake of health promoting behaviours. Feasibility and acceptability were particularly important as this needed to be conducted within significant time and resource constraints common to social care organisations (Spanos, Hankey, Boyle, Koshy, Macmillan, Matthews et al., 2013). Finally, the possibility of creating a wider health promotion culture, through sharing of best practice and influencing organisational policy, was also considered from the outset (O'Leary, Taggart, & Cousins, 2018).

Candidates may also experience resistance to change within the organisation (e.g. other services may compete for priority, or struggle to release staff for training), and it may help to understand, if possible, prior to training where this may arise, through attending to

organisational politics (Rhoades & Eisenberger, 2002). It can also help to enquire with stakeholders into how a trainee may help in their setting or organisation (Schein, 1999) as this may aid development of a training plan.

### **Organisational support**

To assess whether an organisation is suitable for placement and secure an appropriate role, it is important to assess the degree of organisational and supervisor support and build on this if possible. This is based on the principle of organisational reciprocity for employee commitment (Gouldner, 1960). Types of organisational support include: displaying concern about employee welfare, better role conditions such as support to manage stressors and provision of supervisor support (Rhoades & Eisenberger, 2002). This can present itself in practical ways such as giving candidates greater autonomy in managing their workload, facilitating access to continuing professional development (CPD) opportunities, providing protected study time and assisting with the development of a training plan.

Additionally, if senior staff shows interest in how the candidate is progressing as potential trainee psychologist, this can benefit the organisation and their own career development. Furthermore candidates can gain valuable insight into sources of support (Kraimer, Seibert, Wayne, Liden, & Bravo, 2011; Rhoades & Eisenberger, 2002) and potential reach of the role when determining suitability for placement, which in turn can positively impact the candidates self-competence (Battistelli, Galletta, Vandenberghe, & Odoardi, 2016).

Involvement with organisations prior to applying for a professional doctorate, participating in training and development opportunities, and performing tasks to a high standard will lead to good relationships with an organisation. This in turn could lead to more potential placement opportunities for trainees. For example, prior to becoming a trainee psychologist, I worked as a support worker in various services and took projects with clients with complex mental and physical health needs to build my skills and professional reputation. This helped me to secure a placement opportunity as a trainee psychologist within the organisation. It can also help to seek feedback from a supervisor or mentor to ensure better fit between the proposed trainee role and organisational objectives (Parker & Collins, 2010), as this can help to build professional networks which may be useful during training (e.g. facilitate meeting other psychologists in partner organisations).

Furthermore, workplaces may not have a good understanding of the professional psychologists' role. Therefore, communicating how training can benefit the organisation and

clients is important. Potential supervisors can then help to create proposals and facilitate access to clients and research participants. This can take considerable time and effort, particularly when working with hard to reach or underserved populations. Not having support from your organisation could make it difficult to undertake - research and training activities. This includes: teaching staff or conducting interventions with clients or employees and it may then take candidates longer to achieve their competencies as a result. Therefore it is important to build good relationships with organisations prior to beginning a placement.

### **The relationship with the supervisor**

Arguably, the most important relationships during doctoral training are those with academic and workplace supervisors. A workplace supervisor may act as proxy for perceived wider organisational support (Rhoades & Eisenberger, 2002), career mentor and advocate on behalf of a trainee to facilitate access to client groups. They may also help with establishing projects and providing opportunities for development (Kraimer et al., 2011) and help to resolve problems which arise during training. Moreover, a supervisor will also ideally have extensive knowledge of the client group a candidate aims to work with as well as early involvement in development of the training plan at application and interview stages. They can then facilitate implementation of the plan during training, though the candidate will have primary responsibility for devising this when applying to gain entry to doctoral or Stage 2 training.

A workplace supervisor will work alongside an academic supervisor to evaluate a candidates' performance of their competences, may provide written reports of feedback and sign records of attendance and completion. Thus, it is important that they are registered professionals with appropriate bodies, such as the HCPC and ideally, the BPS. If they are not, then a workplace contact may need to be established with these credentials. Ideally the workplace supervisor would be a psychologist in the same or an allied profession (e.g. clinical psychologist for a trainee health psychologist). If a preferred supervisor is experienced at working with the target client group, has influence in the setting and a well-established social network, they may be able to find an appropriate workplace contact for the candidate. Ideally the workplace contact will also have experience working with the target client group and this should be easier if they are found through professional contacts allied to the organisation, such as through multi-agency collaboration or inter-disciplinary team working.

Alternatively, for those undertaking the professional doctorate, the university may be able to arrange for a second supervisor who is a practitioner psychologist, to provide additional input when needed for the trainee or workplace supervisor. Although the secondary supervisor may not have specialist expertise with the target client group, if the main workplace supervisor works closely with the target clients this can be an effective partnership, provided good communication is established early in the training and their role is clear. This will help to ensure that plans made are realistic and trainees are not expected to work beyond their knowledge and skillset.

**Top tips:**

- Develop a good understanding of your target clients and topics of interest. Think about what you would aim to address. Would this involve fostering resilience in professionals working with vulnerable clients and ascertaining impact on staff turnover? Helping service users with mental health issues to manage comorbid physical illness? Supporting football players to reduce rumination on mistakes and assessing impact on performance?
- Take on projects that involve working with people and developing relevant skills that can help with training and make your case for stepping into a trainee role. Examples include recruiting new staff (assessment), working with service users with health issues (providing health information, supporting medical adherence), running exercise workshops (intervention development and planning).
- Learn about experiences of others in the field. This can be through attending a careers talk (these are regularly arranged by the BPS for members as local events), conference and networking events, reading BPS Division publications for your field (free for members: Health Psychology Update, Sport & Exercise Psychology Review, OP Matters).
- Be very clear about how you plan to meet at least some of your competences through your placement when making your application. This can aid your credibility and have real impact on your training journey.
- Maintain open communication with your agreed supervisor during the application process. When you begin training, your organisation will be expected to collaborate with the institution providing the course and this will help your supervisor to coordinate this (e.g. placement visits, registering as your placement provider).

## **Conclusion**

Trainee psychologists in health, occupational and sport and exercise psychology work in varied organisational contexts and prospective candidates may need to be proactive in seeking out an appropriate placement. They may also need to factor in their interests and whether the placement provide opportunities to meet competencies, if funding is available, degree of autonomy in their role and presence of organisational and supervisor support.

Building good professional relationships is also important to help candidates gain entry and begin their journey towards being an applied psychologist.

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## References

- Battistelli, A., Galletta, M., Vandenberghe, C., & Odoardi, C. (2016). Perceived organisational support, organisational commitment and self-competence among nurses: A study in two Italian hospitals. *Journal of Nursing Management*, 24(1), E53. doi: 10.1111/jonm.12287
- Gouldner, A. W. (1960). The norm of reciprocity: A preliminary statement. *American Sociological Review*, 25(2), 161-178. doi: 10.2307/2092623
- Kraimer, M. L., Seibert, S. E., Wayne, S. J., Liden, R. C., & Bravo, J. (2011). Antecedents and outcomes of organizational support for development: The critical role of career opportunities. *Journal of Applied Psychology*, 96(3), 485-500. doi: 10.1037/a0021452
- O'Leary, L., Taggart, L., & Cousins, W. (2018). Healthy lifestyle behaviours for people with intellectual disabilities: An exploration of organizational barriers and enablers. *Journal of Applied Research in Intellectual Disabilities*, 31, 122-135. doi: 10.1111/jar.12396
- Parker, S. K., & Collins, C. G. (2010). Taking stock: Integrating and differentiating multiple proactive behaviors. *Journal of Management*, 36(3), 633-662. doi: 10.1177/0149206308321554
- Rhoades, L., & Eisenberger, R. (2002). Perceived organizational support: A review of the literature. *Journal of Applied Psychology*, 87(4), 698-714. doi: 10.1037/0021-9010.87.4.698
- Schein, E. H. (1999). *Process consultation revisited: Building the helping relationship*. Reading, MA: Addison-Wesley.
- Spanos, D., Hankey, C. R., Boyle, S., Koshy, P., Macmillan, S., Matthews, L. et al. (2013). Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: A qualitative study. *Journal of Intellectual Disability Research*, 57(1), 90-102. doi: 10.1111/j.1365-2788.2011.01530.x

# **Attending the Creative Knowledge Mobilisation workshop at DHP Conference 2018: A review Kiran Bains and Tiece Turnbull**

## **Abstract**

Disseminating knowledge is an important element of practice in health psychology. This can help research to have positive impact in wider society. Digital technologies and social media create a plethora of available avenues for students to share research and practice, but it can be difficult to envisage how creative methods can be used to mobilise knowledge effectively with the public and stakeholders. A creative workshop mobilisation workshop hosted at the DHP Conference for students aimed to address this topic.

## **Background**

As a profession which benefits from taxpayer funding, there is increasing importance placed on demonstrating how health psychology can create impact and benefit wider society beyond traditional academic means, including journal article publication (Higher Education Funding Council of England, 2012). This may also help us demonstrate our knowledge and skills, thus facilitating our profession and career development (Gillison, McSharry, McGowan, Morrison & Shaw, 2017).

## **The workshop**

Prior to the beginning of the DHP conference in 2018, a pre-conference workshop on Creative Knowledge Mobilisation was led by Dr Rachel Shaw and facilitated by Shanu Sadhwani. This is a reflective account after attending this event. The workshop aimed to help students to consider ways in which knowledge gathered through research could be shared with the public, which includes health professionals and populations whose health needs we strive to understand and address.

An early exercise in the workshop was a discussion on the meaning of knowledge mobilisation. Key ideas were sharing information to aid decision making, the interpretive

nature of knowledge and how this evolves. The underpinning argument was '*knowledge is power*' (Foucault, 1983) and mobilising this can impact power dynamics. As such, knowledge mobilisation involves building connections with research users through activities which not only include knowledge transfer, translation and exchange, but co-production of knowledge to inform policy and practice (Phipps & Shapson, 2009).

Students were invited to consider sources of power in their research and how sharing knowledge creatively could empower communities whose health needs we strive to understand and ultimately, help meet. Creativity is important to make knowledge sharing accessible, interesting and actionable for wider audiences, so we discussed potential ways to achieve this in small groups. It was widely agreed early involvement of stakeholders was helpful. We were also shown several examples of how this had been previously achieved, including by Rachel Shaw and colleagues, using video, pictures, art, music and poetry to concisely convey key messages of research undertaken. One focussed on managing frailty (d'Avanzo, Shaw, Riva, Apóstolo, Bobrowicz-Campos, Kurpas, et al., 2017, <https://youtu.be/tOqbiqIQTo>) and another, the effect of diagnosis of Alzheimers' Disease (see <https://kateswaffer.com/poems/> for examples). They variously involved participants, interdisciplinary collaboration, creative researchers and students and well known artworks to convey important messages from the research. Collaboration with others, including digital media or film students, could be mutually helpful if we have clear ideas of how we can share knowledge and with whom. University Research/Exchange services (or a science communication officer) can also provide helpful guidance on public engagement.

Some students shared interest in making film, using pictures or theatre to share results of their research in the future and enable users to explore sensitive issues explored in research. Another informed us of a community space developed after a disaster event for families and children, enabling mutual practical and emotional support through creative activities, including expressive arts and nature projects. Upon reflection, it could be argued that creative knowledge mobilisation could be cathartic by facilitating emotional expression and provide a sense of personal relevance by giving voice to those directly involved in its' creation.

## **Student feedback**

Students at various stages of their qualification journey also provided feedback. Some came with specific projects in mind for creative knowledge mobilisation but others were interested in a general overview. They were pleased with the interactive nature of the workshop, as there was a good balance of teaching and discussion. They felt it was fun and the style of delivery was engaging. Several appreciated opportunities to hear about projects which mobilised knowledge creatively and others' ideas about how this might happen. They also enjoyed meeting other students with related interests prior to the start of the conference in a relaxed environment. Finally, students indicated interest in seeing more content and having further opportunities to mobilise knowledge creatively within their own work. This suggests it could be the start of an ongoing conversation about this topic involving a new cohort of students, early career researchers and applied psychologists.

## **Link to publication:**

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## References

- d' Avanzo, B, Shaw, R, Riva, S, Apóstolo, J, Bobrowicz-Campos, E, Kurpas, D. et al. (2017). Stakeholders' views and experiences of care and interventions for addressing frailty and pre-frailty: a meta-synthesis of qualitative evidence. *PLoS ONE*, 12(7), e0180127. DOI:10.1371/journal.pone.0180127.
- Higher Education Funding Council of England (2012). *Assessment framework and guidance on submissions*. London.
- Foucault, M. (1983). The Subject and Power. In Dreyfus, H. & Rabinow, P. (Eds.), *Beyond Structuralism & Hermeneutics* (pp. 208-226). USA: University of Chicago Press.
- Gillison, F., McSharry, J., McGowan, L., Morrison, V. & Shaw, R. (2017). Showcasing health psychology research: How do we get impact and why does it matter? *Health Psychology Update*, 26(2), 2-9.
- Phipps, D. J. & Shapson, S. (2009). Knowledge mobilisation builds local research collaborations for social innovation, *Evidence & Policy: A Journal of Research, Debate and Practice*, 5(3), 211-227.

## **UNIT 1: GENERIC PROFESSIONAL PRACTICE**

### **Reflection on the journey toward becoming an applied psychologist**

I began my training with some assumptions of what I would gain through completing the professional doctorate and becoming an applied psychologist. I thought that I would gain all the skills and knowledge I needed to work towards reducing health inequalities with adults with learning disabilities and other underserved minority groups. Over time and with reflection, I have learned how development and learning as a psychologist is an ongoing process. I have developed my skills in planning and conducting research at doctoral level, but an early, important lesson was in keeping the scope of my projects realistic and feasible. I also learned to more accurately appraise my knowledge and skillset, but also perhaps more importantly, where I need to learn and develop through knowledge of the research literature, training and experience. Additionally, I have increasingly appreciated the value of developing my networks as a trainee. This has been an important source of opportunities to conduct research and practice activities, mutual social support and finally, feedback and information about how I can improve as a practitioner psychologist.

I first focussed on conducting my research project with the intention of gathering data to inform development of an appropriate behaviour change intervention and my teaching and training. However, my plan was to screen adults with learning disabilities in my organisation for common health problems and develop a behaviour change intervention. I learned, belatedly, that to include adults with learning disabilities that did not have mental capacity to participate in research I would need to apply for approval from an ethics committee in the NHS specialising in social care research. I also unsuccessfully applied for funding for the project and recognised that my initial proposal was unfeasible given the time and resource constraints I faced.

I then decided to conduct an interview study with adults with learning disabilities and carers to understand barriers and facilitators to accessing health promotion. However, a conversation with a student peer led me to apply for a consultation with a senior academic in health psychology at the European Health Psychology Society conference *'Meet The Expert'* event. Professor Marie Johnston heard my proposal and her key criticism arising from the discussion was that I was not thinking as a health psychologist but as an educated lay person. Using theory as well as evidence was important to development of intervention in the field,

so using a theory-based approach to interviewing participants could facilitate this as the constructs could form the themes and guide implementation. As many previous interventions with adults with learning disabilities used social cognitive theory (Bandura, 1986; Bandura, 2001) based approaches, with mixed results, I decided to use this to guide my research. I also felt it could be useful as social support is a key construct in the model and adults with learning disabilities often rely on support of carers with nutrition and activity participation (Smyth & Bell, 2006).

I was aware this could be difficult to conduct in practice, as some mechanisms of action could possibly be too complex for this client group (Willems, Hilgenkamp, Havik, Waninge, & Melville, 2017). I decided to use an iterative approach to interviewing, by approaching carers initially, then service users, with preliminary analyses at each cycle until I had enough data for analysis. It was fortuitous that I interviewed managers of services providing support to adults with learning disabilities first, as this gave me rich data to guide later interviews. This was particularly the case as my interviews with the initial cohort of adults were widely variable in their depth, due to differences in understanding and communication between participants.

Visiting potential participants in person was important to ensure they understood the study and what it involved, as carers often did not read information sheets to explain these to their service users before booking interviews. This was evident as only thirty minutes was allocated for each interview one service I approached and I had asked potential participants with learning disabilities to put aside up to two hours, including breaks, for participation. The other key difficulty was that I invited adults with learning disabilities to have a trusted person present in the interview, and carers discouraged them from using this as they were unavailable to facilitate discussion. As those individuals had sufficient understanding and willingness to participate, we proceeded, but it would have been helpful for some participants to have a person who knew them well to facilitate. Thus, having data from earlier interviews enabled use of specific closed questions for certain participants and check if, for example, viewing pictures could help them to remember what they had learned or aid '*confidence*' as a lay proxy for self-efficacy.

I later also gave an oral presentation on my method for conducting interviews with adults with learning disabilities and the important issue of gauging level of understanding for

participation was raised. In practice, there is very little exploration of this issue in the literature and it is difficult to quantify how much understanding is needed, as it may not be evident until after the interview has begun. As a result, I found it important to build trust and rapport with potential participants before they took part, so they felt able to show discomfort or withdraw from research due to difficulties in participation. This also helped to alleviate any distress from terminating the interview early. One participant with communication difficulties withdrew from the study, but this did not present any issues and they were in a calm, relaxed state when they left. This was an important aspect of maintaining ethical practice, and presenting my work enabled me to reflect on how I dealt with ambiguous situations as a research-practitioner in practice, thus represented an important learning opportunity.

Whilst working on my research protocol, I also arranged some consultancy work on a radio station for a UK Punjabi south Asian audience regarding Type 2 diabetes prevention and management as this is more prevalent in south Asians relative to Caucasians. I had already initially reviewed the literature on the topic before my initial meeting with the client, the radio producer. However, I read (Schein, 1999) and realised I was aiming to approach the consultation as an *'expert'*. This seemed inappropriate as I did not know what their information needs were, what had been previously discussed on this topic by previous health professionals, or the audience demographic. With these questions in mind, I approached the client with a curious orientation to ascertain how I would be able to help them by presenting on Type 2 diabetes prevention and management from a psychological perspective. This entailed a more collaborative approach. I found they had previously had medical professionals give guidance on lifestyle management to prevent and manage diabetes and the audience were an older demographic with some understanding of English. They were particularly interested in discussing the relationship of stress and diabetes but felt it important to include content to aid understanding of diabetes.

My literature review suggested sources of stress for south Asians included difficulties making dietary and physical activity changes in a culturally appropriate manner, as social obligations often took precedence over individual health concerns (Lawton, Ahmad, Hanna, Douglas, Bains & Hallowell, 2008; Lucas, Murray, & Kinra, 2013; Morrison, Douglas, Bhopal & Sheikh, 2014). This also meant that, although alcohol use was common in Punjabi communities, particularly amongst men, alcohol misuse disorders were often hidden and

deeply stigmatised in wider communities. There were also issues of complacency surrounding use of alternative medicine and exacerbated social stigma when considering a transition to insulin injections for those whom would clearly benefit according to clinicians perspectives. Thus, we agreed the topics covered would be understanding and coping with diabetes, lifestyle management from a psychological perspective, medical decision making. This also included engendering collective efficacy (Bandura, 2000) by engaging the wider community.

Stakeholders in the organisation also reviewed content and assisted with translation, though this meant some elements, such as religious events were not mentioned, including alcohol misuse at Sikh weddings or adjusting diabetic regimens for Ramadan, so this was altered. I learned to balance my input as trainee psychologist with stakeholder input as they had better knowledge of their audience and I had greater understanding of how to appropriately apply behaviour change models and techniques to a public health intervention. However, it took longer to deliver these than anticipated, as the organisation, whilst initially agreeing to sign the budget contract, subsequently refused to do so whilst the work was underway. I also realised it took greater depth of input than initially anticipated, though I had increased the budget estimate to allow for uncertainty. I learned, in future, to do a brief scoping review to get an idea of the work involved after meeting a client and potential issues that may arise, establish a budget and signed contract of the work involved, and commence only once this had been signed. This would mean the right amount of time would be invested at the outset, to prevent excessive commitment and minimise risk of budgeting inappropriately. After presenting on this topic at the Division of Health Psychology conference, I also learned about the usefulness of learning from social marketing approaches to evaluation of this public health intervention. As a result, I would pilot a regional campaign first, then aim to assess changes in uptake to south Asian oriented diabetes prevention and management programmes in wards with high concentrations of these communities over a set period of time, pre-post intervention.

My behaviour change intervention with adults with learning disabilities was piloted several months later, using findings from my research and literature review of other interventions in the area. This primarily aimed to change eating behaviour, as firstly, this was perceived to be more inclusive of those with physical impairments. Secondly, several service users in the pilot already engaged with recreational physical activity with the same project. This involved

developing and piloting a subset of assessments to ascertain changes in knowledge, self-efficacy and outcome expectancies regarding healthy eating, as well as perceived social support from peers and carers with service users. Staff involved in the intervention were trained in administering these, to aid consistency.

During the teaching workshops, though there was some didactic learning, most activities aimed to be experiential and learners engaged much more actively with these. However, adjusting tasks was an ongoing challenge, during the pilot and subsequent iterations within other services, to adjust teaching to ability as this varied significantly between users in the same groups. This has been noted by another research group when observing implementation of their interventions in different care homes (Bergström, Elinder, & Wihlman, 2014). I also found it important to establish boundaries regarding acceptable behaviour when teaching as some service users displayed disruptive behaviour which often distracted and frustrated other group members. Additionally, I found it important to establish group membership as entering and leaving mid-session was also disruptive and this was often accompanied by noisy conversation. This also minimised risk of non-service users participating and dominating discussions, but it also resulted in a few users that were ambivalent about participation deciding to withdraw from the intervention. For these users with mild learning disabilities, individual sessions using motivational interviewing may have been more appropriate. This was identified as a future continuing professional development need and opportunities to train in this did not materialise, at university or within the organisation, due to resource constraints. Thus, this remains a future goal to develop further as a health psychologist.

The intervention workshops were refined after feedback from co-facilitators and follow up assessment of service users. These suggested service user knowledge, outcome expectancies, self-efficacy and perceived social support had not improved. However, several service users did not take part in post-intervention assessments and this did not happen in the timely manner aimed for at the outset due to service user and co-facilitator unavailability for administration. After this, workshops took place in care homes, to facilitate engagement with staff and improve positive social support, though uptake was variable. Cooking sessions also took place at the end of the education sessions as clients were eager to participate whilst education sessions were shortened and simplified. This also meant cooking sessions could be linked to content in the education session, such as using ingredients that had been discussed in the latter. Participants were prompted to recall benefits of ingredients after they had used

them, aiming to engage them in experiential and to an extent, abstract learning, if within their capabilities (Kolb, 1984).

During this period, I also completed the learning and teaching assessment module of the MA Academic Practice offered by City, University of London. As a result, I developed greater ability to apply use of learning theory to teaching workshops with staff and service users with learning disabilities. I was aware from my and others' previous research, and experience working with this group, that adults with learning disabilities particularly learned from experience, and struggled with abstract concepts (McDermott et al., 2012). Thus, I simplified teaching, used visual and tactile materials, and involved them in games where possible, to stimulate engagement and learning. I also learned to structure my sessions more effectively. This meant co-facilitators whom were not previously experienced working with adults with learning disabilities or delivering the intervention, were able to perform their role with greater effectiveness. I also planned the adaptation of learning resources to individual groups to match learning abilities, whilst meeting set learning objectives. This also helped when developing teaching sessions with staff, to engage them in appropriate application of behaviour change strategies when supporting clients with learning disabilities with healthy eating. The depth of exploration of behaviour change concepts (abstract conceptualisation) and application to theoretical scenarios depended on session length (active experimentation, Kolb, 1984). Sessions held with members of staff from different services enabled greater knowledge sharing between staff with different levels of expertise (Lave & Wenger, 1991), but it was not possible for all interested to attend. This meant staff cover needed to be sought during their attendance, and staff shortages have been noted by several previous studies examining barriers to health promotion and disease prevention with adults with learning disabilities (Cartwright, Reid, Hammersley, & Walley, 2017; Dixon-Ibarra, Driver, Vanderbom, & Humphries, 2017; O'Leary, Taggart, & Cousins, 2018).

Conducting intervention workshops in service users' homes also presented its' own opportunities and challenges. A greater number of service users took part in sessions due to convenience and accessibility, it was easier to tailor content to ability, observe staff practices, engage them during service user workshops and deliver separate staff teaching sessions according to service need. Non-users were also peripherally engaged through testing healthy cooked food, to encourage future engagement. However, this also meant some service users participated, that were not able to understand the sessions due to their increased severity of

learning disabilities, though they took part through food tasting to aid positive sensory reinforcement of healthy eating behaviour (Fahmie, Iwata, & Jann, 2015). Additionally home environments may not always have the facilities or ideal layout for teaching. Some teaching took part in the common area in group homes, which were narrow or did not have tables, making it difficult to include all participants or separate them for small group activities. Service users also varied in the utensils they had for cooking and their understanding of time. Thus additional equipment was sometimes taken to facilitate sessions and make cooking more accessible, such as using colour-coded timers to tell participants how long they would need to bake some items for.

Cooking sessions with larger groups was difficult, as it was challenging to keep service users engaged in sessions. They were all encouraged and supported to make food items, but this could take a significant amount of time and only involved two to three learners at a time due to limited kitchen facilities. This resulted in lengthier waiting times for others, though they were encouraged to observe the process, with mixed success. Additionally, research by Foti, Menghini, Alfieri, Costanzo, Mandolesi, Petrosini et al. (2017) suggests adults with Downs' syndrome may have difficulties learning by observation relative to practising activities, whereas those with Williams' syndrome show the opposite. It is possible the underlying cause of learning disabilities for users can have impact on how they learn most effectively (Foti et al., 2017), so using different modalities to suit different users in a group is important. As this research is still relatively in its' infancy, it would be worth monitoring as if this is the case, it would also inform my future care staff teaching and training on how they may aid knowledge and skill development with their service users.

Ideally, in future, with more resources, a training kitchen could also be used with more cooking equipment, so learners could cook individually or in small groups with staff support. However, in this context, I learned to prompt the facilitator and staff present to engage service users with discussion about how the food they were making related to what they had learned, such as health benefits of spinach consumption. I also collaborated with the [Opening Doors] project to pilot a peer support initiative from a volunteer with learning disabilities to cook with interested individuals when the group intervention had finished. We also collaborated with service users that had previously taken part in cooking sessions to pilot making picture recipes and internet cooking videos with simple healthy meals. These were

for perusal by service users in the wider organisation which they could then do individually with staff as part of their support.

Finally, the last important part of development as a trainee psychologist has been when disseminating my research and practice activities. This has included conference presentations and writing articles for publication. I have learned to tailor my articles for different audiences, including service users, lay professionals and in academic contexts. The most important element of learning was to understand when to explain concepts and activities undertaken in depth such as with service users, and when to adapt written style and prioritise conciseness for journal submission. I have also re-examined my assumptions of others' knowledge through attending and presenting at conferences and this has given me opportunities to reflect and gain new information for future development of my practice.

Overall, I have learned as a trainee health psychologist to plan and deliver more realistic and feasible research and practice projects, accounting for time and resource constraints. I am better able to understand my continuing professional development needs as a research-practitioner beyond my training. This has occurred through development of academic and organisational networks and monitoring opportunities for training and career progression within the field of health psychology. As I develop my skills and knowledge in specific areas I am better able to identify avenues for ongoing supervision with supervisors that have relevant expertise. Additionally, I have established greater awareness of my role as doctoral student in health psychology within workplace and academic contexts through presenting talks and writing an article related to this in a publication. This has also occurred through delivery of intervention workshops and teaching and training within my work placement and as consultant for a radio station. By upholding ethical practices, maintaining accountability and a professional code of conduct, I hope to have helped enhance reputation of the profession of health psychology in these wider contexts.

## References

- Bandura, A. (2000). Exercise of human agency through collective efficacy. *Current Directions in Psychological Science*, 9(3), 75-78.
- Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, 52(1), 1-26. 10.1146/annurev.psych.52.1.1
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, N.J: Prentice-Hall.
- Bergström, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities-a qualitative study. *Health Education Research*, 29(2), 259-271. 10.1093/her/cyt111
- Cartwright, L., Reid, M., Hammersley, R., & Walley, R. M. (2017). Barriers to increasing the physical activity of people with intellectual disabilities. *British Journal of Learning Disabilities*, 45(1), 47-55. 10.1111/bld.12175
- Dixon-Ibarra, A., Driver, S., Vanderbom, K., & Humphries, K. (2017). Understanding physical activity in the group home setting: A qualitative inquiry. *Disability and Rehabilitation*, 39(7), 653-662. 10.3109/09638288.2016.1160294 Retrieved from <https://0-doi-org.wam.city.ac.uk/10.3109/09638288.2016.1160294>
- Fahmie, T. A., Iwata, B. A., & Jann, K. E. (2015). Comparison of edible and leisure reinforcers. *Journal of Applied Behavior Analysis*, 48(2), 331-343. 10.1002/jaba.200 Retrieved from <https://0-doi-org.wam.city.ac.uk/10.1002/jaba.200>
- Foti, F., Menghini, D., Alfieri, P., Costanzo, F., Mandolesi, L., Petrosini, L., & Vicari, S. (2017). Learning by observation and learning by doing in Down and Williams syndromes. *Developmental Science*, 0(0), e12642. 10.1111/desc.12642 Retrieved from <https://doi.org/10.1111/desc.12642>
- Kolb, D. A. (1984). *Experiential learning: Experience as a source of learning and development*. Englewood Cliffs, NJ: Prentice-Hall.

- Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. Cambridge: Cambridge University Press.
- Lawton, J., Ahmad, N., Hanna, L., Douglas, M., Bains, H., & Hallowell, N. (2008). 'We should change ourselves, but we can't': Accounts of food and eating practices amongst British Pakistanis and Indians with type 2 diabetes. *Ethnicity & Health, 13*(4), 305-319. 10.1080/13557850701882910. Retrieved from <https://doi-org.wam.city.ac.uk/10.1080/13557850701882910>
- Lucas, A., Murray, E., & Kinra, S. (2013). Health beliefs of UK south Asians related to lifestyle diseases: A review of qualitative literature. *Journal of Obesity, 2013*. Retrieved from <https://doi.org/10.1155/2013/827674>
- McDermott, S., Whitner, W., Thomas-Koger, M., Mann, J. R., Clarkson, J., Barnes, T. L. et al. (2012). An efficacy trial of 'steps to your health', a health promotion programme for adults with intellectual disability. *Health Education Journal, 71*(3), 278-290. 10.1177/0017896912441240
- Morrison, Z., Douglas, A., Bhopal, R. & Sheikh, A. (2014). Understanding experiences of participating in a weight loss lifestyle intervention trial: A qualitative evaluation of south Asians at high risk of diabetes. *BMJ Open, 4*(6), e004736. 10.1136/bmjopen-2013-004736
- O'Leary, L., Taggart, L., & Cousins, W. (2018). Healthy lifestyle behaviours for people with intellectual disabilities: An exploration of organizational barriers and enablers. *Journal of Applied Research in Intellectual Disabilities, 31*, 122-135. 10.1111/jar.12396
- Schein, E. H. (1999). *Process consultation revisited: Building the helping relationship*. Reading, MA: Addison-Wesley.
- Willems, M., Hilgenkamp, T. I. M., Havik, E., Waninge, A., & Melville, C. A. (2017). Use of behaviour change techniques in lifestyle change interventions for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities, 60*, 256-268. 10.1016/j.ridd.2016.10.008

## UNIT 2: CONSULTANCY COMPETENCY

### Delivering radio talks about Type 2 diabetes prevention and management for a Punjabi South Asian population

Setting:

██████████

Client:

Radio Producer

#### **Aims of the consultancy:**

- To devise evidence-based talks about Type 2 diabetes prevention and management for a Punjabi speaking UK South Asian audience
- To focus on the psychological aspects of diabetes prevention and management, as well as coping with the illness
- To deliver these talks in Punjabi using accessible and culturally relevant communication

#### **Setting up the consultancy:**

In March 2016, I approached the radio producer of ██████████ through a family contact who is a radio presenter at the station, to enquire if they had an interest in having a trainee psychologist deliver a talk, or a series of talks, on Type 2 diabetes. I was aware that there is substantial evidence in the literature that this is highly prevalent in the south Asian diaspora relative to Caucasians in the UK. Having Type 2 Diabetes was also associated with greater morbidity and premature mortality in UK South Asians. They expressed an interest in me delivering the talks as I was able to demonstrate that I had good understanding of the area as a trainee psychologist, relative to their knowledge base as laypersons. Previous research also suggests word of mouth is an important way to communicate health information in south Asian communities (Morrison, Douglas, Bhopal, & Sheikh, 2014). As they knew their likely audience and how best to present the information to them, I decided a collaborative approach would be most effective in this context (Schein, 1999). As I am a '*cultural insider*' with a family history of Type 2 diabetes, I hoped to deliver information that was culturally appropriate for this audience.

We set up an initial meeting to discuss this. I re-reviewed the literature in the area before our meeting, so I could be prepared and well-informed about what issues may need to be addressed in the radio talks with the audience and make suggestions to the producer about topics to cover. I did not know what information they had previously given, and what they wanted me to cover in greater depth. In our initial meeting, I sought to '*access my ignorance*' (Schein, 1999) and find out how I could help. I also did not know exactly what demographic the station engaged in terms of religion, education and social status (castes) of listeners. I thought it important to bear these in mind if possible as they may have an important influence on beliefs and practices (e.g. alcohol use and religion) and therefore intervention content.

The producer informed me they had had previous talks about diabetes by medical health professionals and specialist nurses, but not from a psychological perspective. He particularly wanted me to talk about coping with diabetes. I was aware that this would encompass the audience having a good understanding of diabetes aetiology and management, so we both agreed that I would also cover these topics, as well as touch briefly on mental health and stress management (as the latter had been raised as important in previous research). The areas I aimed to cover were understanding diabetes, making lifestyle changes and medical decision making. I agreed that the work would be done on a voluntary basis as it is within a volunteer-run organisation. The scope of this was agreed and I wrote the contract and minutes of the meeting as such (See Appendix A).

### **Deciding on appropriate theoretical frameworks to guide the intervention**

After this I reorganised my literature review into barriers and facilitators to diabetes prevention and management in South Asians, giving greater weighting to studies that were most relevant and/or robust. I additionally looked at intervention mapping as a guide (Kok, Bartholomew, Parcel, Gottlieb & Fernández, 2014), as previous research had used this approach with South Asians to help them change their lifestyle behaviours. I decided to use Levanthal's (1980) self-regulatory model to guide my work on helping the audience understand diabetes and Bandura's (2000) concept of collective efficacy. After discussion with my academic supervisors, I also decided to use the Theoretical Domains Framework (TDF, Cane, O'Connor & Michie, 2012) and the Necessity-Concerns Framework (NCF, Horne, 2003). This helped me decide on appropriate evidence-based behaviour change techniques for lifestyle change and medication adherence, based on my knowledge of the literature (pairing them with the barriers and facilitators I identified in my literature review) and to guide my talk on medication (providing information to address misconceptions which

could impede effective diabetes management). My only concern was that I would need to stay within the limits of my role as a trainee health psychologist. I also did not want to portray myself as an expert in the area, as I did not conduct this research myself, so I asked the presenter to introduce me as a student so that the audience were informed of this. Further, I would not be able to give specific advice about diet or medication changes for callers. I therefore sought to address this by collaborating with a specialist diabetes nurse. I asked the radio producer if they could invite one of their contacts to the talks with me to address these topics if callers phoned in with their queries. Whilst he initially agreed, this did not materialise in the end (See Appendix B).

### **Issues with getting contract and budget signed off**

The content of the talks had been agreed and I gave my research findings to the radio producer. He said he needed it not in full form of the theoretical frameworks I had used, but in the form of questions and answers as it was too '*academic*'. When I gave this to him in question and answer format, he was instantly reassured and told me that was something they could work with. I chased the contract explaining that I needed it for my portfolio, and he signposted me to the board of trustees. I emailed the board and they asked me to write a letter to confirm it was being done on a voluntary basis, which I did and sent promptly (please see evidence folder). They then said they needed to speak to my supervisors and had tried to contact them but to no avail; it transpired they had not contacted my primary supervisor. I had no further responses, so I asked a contact within the organisation, informally, to tell me what was happening so I could ascertain whether the talks would go ahead. I also had written confirmation from my course director that this was not necessary, but as my supervisor pointed out, negotiating a budget is key skill in arranging a consultancy contract. My only counter is that it was done voluntarily so may not accurately reflect the process when payment is involved. It was useful, however, to quantify the value of my work and input, the likely length of time it would take and resources that could be useful in delivering the intervention (e.g. an Asian eat-well guide).

### **Deciding on the structure and content of the talks**

I decided to explain the causes of diabetes and give an overview of how it could be prevented and managed first, following the core constructs of Levanthal's (1980) self-regulatory model (See Appendix D for an overview of use of theory to underpin content). Key to this was deciding upon the right analogy and I referred back to one that had been successfully used in

a previous public health intervention with a south Asian and medical audience (Patel, Stone, Hadjiconstantinou, Hiles, Troughton et al., 2015). This was of insulin acting as a key, used to allow fat and sugar into various parts of the body, as I would return to this throughout the subsequent talks. For this topic I sought to strike a balance between disrupting the ‘normalisation’ and inevitability of diabetes, which presented as a key issue in the literature with this population, with being supportive of adaptive psychological coping. I aimed to minimise cognitive disengagement by pairing information that might concern an audience with ways they could change their behaviour to adapt to these issues, to effectively engender behaviour change. My next topic was about diet, physical activity, and after some reflection, alcohol use in diabetes. I wanted to also give suggestions on dietary change and increasing physical activity, but without inviting expectations of dietary prescriptions. To achieve this, I began to invite listeners to think about asking questions with a psychological focus (e.g. encouraging reflection on how they could better support others to manage their diabetes as a community).

I also aimed to touch upon topics such as gender inequality in managing diabetes, but without raising defensiveness. I therefore chose a gender-neutral approach when talking about obstacles to diet change within a family context if one individual is responsible for shopping and cooking for a family. This was done by contrasting when an entire family opts to change their diet as a result of one person having diabetes with a lone person trying to make dietary changes in isolation rather than with support and engagement from wider family. I also began to use my own experience, and that of my family, to act as relatable role models for people aiming to prevent and manage diabetes through lifestyle change. I was careful to separate this explicitly for the audience from when I spoke about research findings to try to persuade my audience to engage in health behaviour change, rather than for my own benefit. I also focussed on using culturally appropriate examples of behaviour substitutions. For example, a commonly held belief is that lemon water is beneficial to health. I encouraged people to drink hot lemon water to redirect them from eating hot food after walking in cold weather to warm up, to reduce excessive calorie intake.

I initially did not want to talk about alcohol misuse as this culturally taboo and I was unsure of how to address this issue. In most religious contexts, for Punjabi communities, alcohol use is forbidden, yet it is a common cultural practice in Sikh weddings, for example. Previous research also suggested that alcohol problems were a common concern among Sikh men. I was, however, not given permission to bring up the topic of religion on the talks at all, as it is

a very sensitive subject. As a result, I sought advice from my contacts at the station and reflected on how to discuss this in a more tactful, neutral way. I decided to use humour by referring to a well-known popular folk song on the subject and talk about alcohol use in a neutral context (e.g. when attending parties), in a non-judgmental way, encouraging listeners to also adopt this approach. Finally, I signposted people to further help if appropriate. This was responded to well by my contacts and the radio presenter.

For my final talk, I decided to address medication issues. The Necessity Concerns Framework (Horne, 2003) was very useful in this context. I wanted to address the assumption that using alternative medicine would be helpful, or at least, cause no harm. I also aimed to address the fears and misconceptions around insulin use without suggesting that it was a panacea for effective diabetes management. I explained that whether this would be appropriate would still depend on the person's' circumstances, and the decision about whether to progress to insulin use still lay with the person and their medical team. I referred to the analogy of insulin as a key and elaborated on this a little by explaining that some oral medication would '*oil the key*', whereas other medication would '*oil door locks*'. This was also useful when talking about refraining from making assumptions about how alternative medication could work. I was able to use a vegetable related to '*keralla*' as an example. This is widely considered a delicacy in India, and additionally as having medicinal properties, a belief also shared by sections of the Punjabi community which was being investigated by Diabetes UK for how it may impact the condition. I outlined two ways it could work theoretically and how this could impact how it should be consumed, along with our lack of knowledge of the mechanism of this. If it works as a normal vegetable, for example, it may need to be consumed as part of a balanced healthy diet, but if it actively lowers blood sugar after a meal, it may need to be consumed afterward in a structured dose. When deciding the questions that the presenter would ask me before hand, I sent it all out in a question and answer format. The day before the first talk, however, the producer reviewed my questions and edited these for this talk, which I found out about later on in the evening. This was quite stressful as it meant I could not plan ahead well. The questions were basic questions about diabetes symptomology and checks, which in hindsight I would include myself as these are standard topics. I did not get much time to practise this material in Punjabi and found it unsettling, particularly as this would be my first time being in the media spotlight. By the second and third talks, I had learned to significantly re-word the content so it was less of a narrative and more focussed on the questions and answers becoming individual units of

information. However, I also needed to balance this with building on my analogy of insulin acting as a key within the body so that food could be used for energy, to aid explanation and coherence where appropriate (Thagard, 1989). This was repeated where appropriate to explain how certain medications may work. Following these adaptations, the latter two talks were accepted by the producer without further editing and minimal re-working of the material.

### **Phone-ins**

To prepare for possibly dealing directly with phone-in calls I prepared crib sheets for onward referrals to various organisations, if fielding questions outside of my knowledge or remit. I also spoke to the producer about involving a diabetes specialist nurse or doctor, in the talks, and doing these collaboratively, so they could give more tailored information directly about these topics to the audience. He initially agreed to this, but this did not materialise in the end. I also enquired at a local diabetes specialist project to see if I could find out about their work as they run self-management groups with a view to possibly seeing if they could be engaged within the talk, but they did not respond to my enquiries. Additionally, the radio station would also need to permit this and they may have been reluctant as they seemed to prefer to be in control of exactly whom would be presenting. As it turned out, as there was a significant amount of information given in the talks, and as I still needed more practice time in Punjabi than what was available, time for phone ins were minimal, and mostly dealt with by the presenter.

I got some positive feedback that the content was culturally appropriate and understandable for a lay audience, and praise for trying to engage with my audience in Punjabi (See Appendix E for evaluations). I was also advised against using a mix of both English and Punjabi, so in future I would need to be more practised and fluent (particularly in talking about health-related topics). This would enable me to address language barriers and engage more fully with the segments of the audience who could benefit from it most directly in this community.

### **Reflection: depth of review**

Doing a literature review before the meeting was necessary, to have an informed perspective on the area. The initial review, however, was perhaps too thorough as it took considerable time to update and record my findings for later use, so this involved a considerable investment in time and effort. In future, I would do a scoping review first, to see what might

need to be addressed and the work involved, so that I could budget it accurately. Conducting an in-depth review may also mean I am invested in a particular course of action, which is not necessarily what the client will want. This may not be quite such an issue if it is a research topic I know well, but some of the consultancy work I undertake in future may involve a certain amount of novelty and preliminary research on my part. I devised a budget, based on a rough estimate of what I would be paid to do this in a paid post as a research assistant and how long it would take to do a review and synthesise that into an intervention. Given the delays it caused later, however, I would in future have a signed contract with my recommendations, before I undertook any subsequent work. This way, for future paid contracts, if they choose to pay me part of a fee, we could agree on what recommendations would be acted upon before it is carried out.

### **Reflection: Switching between different modes in the consultancy**

Schein (1999) argues that at different points in the consultancy, a consultant may switch between different modes. At times I was the *'expert'*, taking a lead on researching the issues at hand and deciding what theoretical frameworks and BCTs would be useful for the intervention. At others, when translating to Punjabi, tailoring content to the audience and considering what would be acceptable by a speaker at the station the radio presenter, the producer and my family contact gave me invaluable input to edit my talks for these outcomes. There were times, however, where I had to assert myself in keeping content as I was working with laypeople, and some of it seemed counterintuitive to them (e.g. when using some concepts derived from mindful eating practices).

### **Reflection: Key barriers arising in the consultancy**

Another key barrier is that there were certain things agreed to in the earlier meetings by the producer which were not delivered, namely a signed contract and budget, and this caused considerable delays and difficulty. It was difficult at times, to work in such an informal context where I was providing most of the structure and took some self-awareness to work within my boundaries and remit. This was also important to contain the amount of work I undertook in the consultancy, rather than agreeing to more work than originally planned, as this would have been impractical and resource intensive to deliver.

## References

- Bandura, A. (2000), Exercise of human agency through collective efficacy. *Current Directions in Psychological Science*, 9(3), 75-78.
- Cane, J., O'Connor, D. & Michie, S. (2012), Validation of the Theoretical Domains Framework for use in behaviour change and implementation research. *Implementation Science*, 7(37).
- Horne, R. (2003), Treatment perceptions and self-regulation. In Cameron, L.D. & Levanthal, H. (Eds.). *The self-regulation of health and illness behaviour* (pp. 138-153). London: Routledge.
- Kok, L.G., Bartholemew, K., Parcel, G.S., Gottlieb, N.H. & Fernandez, M.E. (2014), Finding theory and evidence-based alternatives to fear appeals: Intervention Mapping. *International Journal of Psychology*, 49(2), 98-107.
- Levanthal, H., Meyer, D. & Nerenz, D. (1980), The common sense representation of illness danger. *Medical Psychology*, 2, 7-30.
- Morrison, Z., Douglas, A., Bhopal, R. & Sheikh, A. (2014), Understanding experiences of participating in a weight loss lifestyle intervention trial: a qualitative evaluation of south Asians at high risk of diabetes. *BMJ Open*, 4(6).
- Patel, N., Stone, M. A., Hadjiconstantinou, M., Hiles, S., Troughton, J., Martin-Stacey, L., et al. (2015). Using an interactive DVD about Type 2 Diabetes and insulin therapy in a UK South Asian community and in patient education and healthcare provider training, *Patient Education and Counseling*, 98(9), 1123-1130.
- Schein, E. H. (1999). *Process consultation revisited: Building the helping relationship*. Reading, MA: Addison-Wesley.

## Appendix A: Contract and budget

### 1<sup>st</sup> Meeting with radio producer – 24.06.16

Attendees: Kiran Bains (KB), Ajit Khaira (AK)

Minutes:

- Talked about background and previous talks (including those by IAPT team).
- Discussed topic areas for delivering radio talks – diabetes understanding, coping, lifestyle management, fears and myths regarding insulin injections agreed upon (particularly first two as focus).
- Have had many talks from medical perspective: now looking for psychological perspective.
- Need to ‘concretize’ information, not keep abstract.
- Punjabi-speaking audience of all ages.
- Format is Q&A session – questions prepped by KB, to be answered. Initial talk will not involve phone-in to ease person in.
- Shared barriers and facilitators list to diabetes prevention and management in this population.

KB to do:

- Put research into evidence-based framework.
- Look at coping literature.
- Get a health psychology mentor to supervise.
- Budget project.

AK to do:

- Look at barriers/facilitators list.
- Think on anything else that needs to be addressed, or ways to address it to meet needs of audience.

### **Budget:**

£13/hr

Researching barriers and facilitators – 45 papers read + searching to do, critiquing and putting into appropriate format (2.5 weeks) - £1300

Researching appropriate frameworks to guide intervention (2 weeks - £1040) – Intervention mapping, Levanthal’s’ Self-Regulatory Model, Theoretical Domains Framework

Researching appropriate consultancy model – appropriate: 3 days - £312

Putting intervention into appropriate format for audience (1 week – £520).

Meetings - £13 each

Developing talks – 2-3 hrs each (£200) – 4-5 talks (£800-1000)

## Appendix B: Minutes of Meetings

### Radio talks – Type 2 Diabetes and a Punjabi audience

Attendees: Kiran Bains (KB), Dr Kathleen Mulligan (KM)

Minutes:

- KB went over background and rationale for doing radio talks. South Asians at greater risk of T2D than Caucasians in the UK. Targeting Sikhs as better to work with people on a 'deep level' of their identity rather than South Asians as a whole, though considerable overlap in beliefs and practices.
- KB talked about initial meeting with radio producer:

Q&A format. Initial talks not a phone in.

Topics: Understanding diabetes, coping, diet/exercise, insulin injections (fears and myths)

Based on Levanthal's CSM

- KMs concerns: drifting into diabetes specialist role (especially if people phone in with specific questions about their diet or exercise levels), not appropriate. Need to stay general.
- KB has contacted authors of 2 previous trials to ask if there are any resources they can share that can be useful for this audience (e.g. Punjabi eatwell plate). No response yet.
- KB to do:

Look at past contracts from DPsych Health portfolios

Finish looking at coping literature, integrate into CSM framework.

Send to Kathleen: barriers/facilitators list, Evidence in CSM framework with citations attached, key intervention study info

Arrange meeting with her and Renata

See if a diabetes specialist nurse can be found to advise on nutrition and exercise

## 2<sup>nd</sup> Meeting with Radio Producer – 27.07.16

Attendees: Kiran Bains (KB), Ajit Khaira

Minutes:

- Discussed tasks from last meeting:
  - AK found the barriers/facilitators list too abstract and removed from being able to produce talks. Need to use concrete examples.
  - KB showed AK Levanthal's' self-regulatory model (SRM) – framework used to guide talk (especially re understanding diabetes) and has started putting evidence into that framework.
  - KB has a mentor. Mentor asked to ensure that KB does not give specific advice re lifestyle adjustments to callers, as this is the role of a diabetes specialist nurse/dietician. KB asked if it is possible to have one involved. KB or AK may be able to contact one.
  - KB still looking at coping literature re T2DM and South Asians. Broadly categorised as approach/avoidance coping.
  - KB produced contract and budget.
- AK reminded KB that Punjabi speaking, rather than Sikh audience per se (variety of religious affiliations): be careful discussing religious practices and adjust contract to reflect this.
- Discussed a scenario where South Asian people may struggle with eating and drinking in moderation: weddings. Discussed issues (whether accepting hospitality is part of it, motivations) and ways that people may deal with it (e.g. small plates, eating slowly). KB to consider looking into signposting people toward 'mindful eating' as one temptation raised may be to consume food quickly and in great quantities as it may just be present. KB talked to AK about need to collaborate as an 'insider' who may know how to relate messages to a Punjabi audience on basis of experience.
- Probably involve delivering 4 talks in total.

KB to:

- Adjust contract and budget to reflect Punjabi, rather than Sikh, audience.
- Finish looking at coping literature in South Asians and put it into Levanthal's' SRM as framework.
- KB to look at 'mindful eating', see if appropriate.
- KB to look to see if there is any relevant research on Ramadan and healthy eating, to see if anything helpful can be gleaned.
- Ask family re: contacts with diabetes specialist nurse.
- Start planning what can be addressed via radio talks.

AK:

- Get contract signed by chair.
- Pass on details of contact in local IAPT team (relevant when talking about coping and distress, and addressing audience).
- Look at finding a diabetes specialist nurse to collaborate with regarding lifestyle modification talk.

**[REDACTED] talks – meeting with academic supervisors  
05.09.16**

Present: Kiran Bains (KB), Renata Pires-Yfantouda (RPY), Kathleen Mulligan (KM)

Minutes:

- KB updated RPY and KM about progress:
  - KB has put research into Levanthal's' SRM framework
  - KB worked on addressing barriers and facilitators (diabetes understanding, prevention and management through lifestyle, treatment issues) using information provision based on research, the concept of collective efficacy, role-modelling, coping (active and avoidant), engendering social support, challenging misconceptions and signposting
  - Looked at Diabetes UK and NPR
  - Contacted authors of other studies with mixed results
- KM - very important to stay within boundaries (not giving advice about medical treatment, and staying neutral about medication options, or e.g. prescribing a specific diet), not acting as diabetes specialist
- KM – representing City University
- RPY – Can give some practical guidelines (e.g. diet, PA) using resources available. Can look at public health studies for resources, reach out via BPS to clinical psychologists working within diabetes in south Asian population (possibly attend a meeting or share resources?)
- RPY – Reflective, curious, open approach. Not an expert in area but pulling together research and theory (e.g. locus of control), putting together with understanding as cultural insider to reach out to hard-to-reach group, distinguish between what evidence says and own perspective (but don't get too formal re research as do not want to alienate them)
- KB – will share some personal perspectives and experiences when appropriate but make clear that they are personal
- RPY - List some topics/themes that may come up and some quotes/resources you can signpost people to
- RPY – may not have all the answers, important to be honest. Perhaps can get callers' details and send some information to them or put up on site? Check with Radio producer
- RPY – evaluation methods could be several: listening figures (ask radio producer), feedback from radio producer, reflective entries. KB – evaluate how well tie content into theory and BCTs. Reading Behaviour Change Wheel
- KM – look at TDF, Levanthal's' extended SRM (behaviour beliefs, treatment beliefs, interaction with illness beliefs), necessity-concerns framework
- Look at barriers/facilitators list (and evidence), pull together into framework and look at links between them to understand how cognitions may impact behaviour
- KB – may be able to get diabetes specialist involved
- KB – hoping to start hosting talks in October, as a series

Action points:

- KB to link research collected to Levanthal's' extended SRM (beliefs about behaviour and treatment, and link this to cognitions)

- KB to look at models on coping, locus of control, TDF, BCW and link plan on addressing barriers and facilitators to this where possible
- KB to make explicit (if not done already) when ideas to address issues come from perspective as insider rather than previous research (using theory where possible)
- KB to make a list of themes and quotes/resources underneath to be able to give appropriate answers about areas which are uncertain/out of remit (e.g. signposting)
- KB to send info on plan to address barriers and facilitators for feedback to KM and RPY
- KB will reflect on this meeting and progress so far
- KB to get in touch with clinical psychologist specialising in diabetes in local area to ascertain if can attend any meetings/gather any resources
- KB to look at public health studies and chase up researcher in Manchester re any dietary/physical activity resources

## Meeting with Ajit Singh (Radio producer) 19.10.16

Present: Kiran Bains (KB), Ajit Singh (AS)

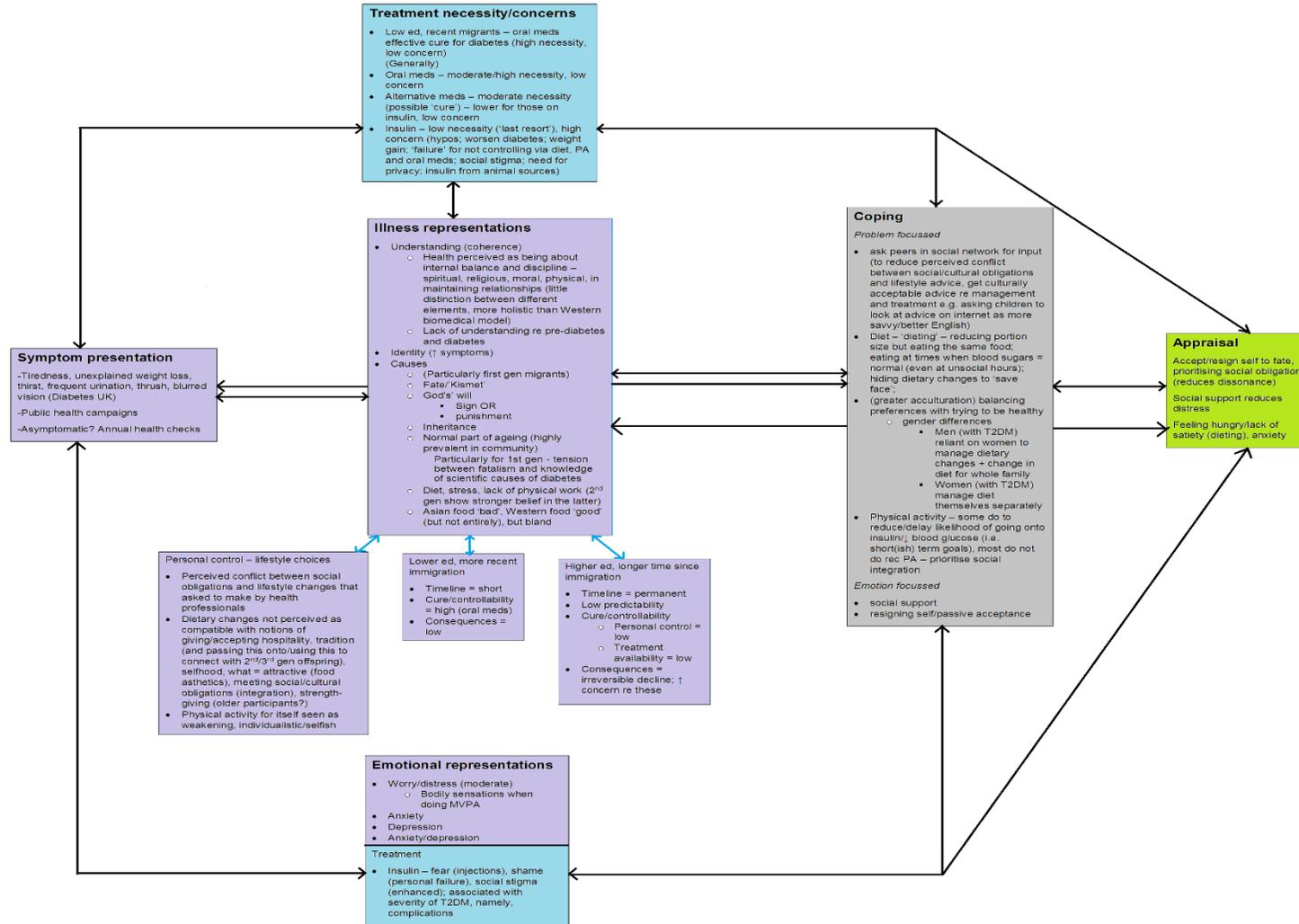
Minutes:

- KB has produced a table with BCTs and strategies used to address barriers and facilitators to diabetes understanding, prevention and management in this population
- KB has put information about medication and insulin use beliefs in the NCF and outlined BCTs/strategies to deal with these issues where appropriate
- KB has put the information about cognitive and emotional illness representations into Levanthals extended self-regulatory model (diagram) and linked these together where these are known.
- KB has used this information to draft her Q&As for the radio talks (covering understanding, prevention and management through attending checks, coping, diet, physical activity and medication).
- AS was happy with this as this is something he can help with and evaluate.
- KB has included appropriate signposting for various issues (e.g. Diabetes UK, IAPT services, GP, Alcohol Concern, local diabetes structured education services for south Asians) in the talks.
- KB has encouraged people, in the talks, to comment with their thoughts on how people may change their behaviour (to focus on psychological aspects of coping with diabetes, rather than prescriptive guidance on lifestyle and medication management).
- AS has said all the talks will be recorded, including phone in questions, and can be saved as a podcast, which can be linked.
- Listening figures not available.
- KB met with science media contact at City, happy with steps taken to broadcast responsibly, following meeting with academic supervisors.

Action points:

- AS to see if he can get a nurse/diabetes specialist in to talk specifically about diet and physical activity changes.
- KB to send Q&A to supervisors to check they are happy with it.
- AS to help KB translate it into Punjabi in way that listeners can relate to.
- KB to meet with Trustees to discuss budget and contract as cannot go ahead without sign off.

# Appendix C: Design of talks (Application of Theory)



## Intervention mapping in diabetes prevention and management

### General

<b>Barriers</b>	<b>Facilitators</b>	<b>BCTs/Strategies</b>
Lack of policy and service provision (1)	Spoken interaction, in own language (ideally face-to-face), word of mouth (2, 6)	
Low/no literacy and language barriers (1, 4, 6, 7, 8, 9, 20) – having to rely on family as translators and not wanting to burden them so not asking all the questions they want to (6); health care professionals feeling that that also impairs rapport (7); not being able to get help if had an injury whilst doing PA (20)	Verbal communication that is good, empathic and compassionate (2)	Speak in Punjabi, practical advice to overcome language barriers in wider social context when needing help, engendering social support.
Peers are a big influence on beliefs (8)	Communication via media may be effective – e.g. DVD ‘drama’ (3) (roleplay?)	Collective efficacy – mobilise community; engendering social support; encouraging role modelling of healthier behaviour
Elders in family particularly may give advice or instructions on diabetes which may or may not be sought (8)		Changing negative social support into positive social support
Going to specially organised events may not be possible due to time commitments, prioritising own family commitments first (6, 8)		Giving general guidelines and signposting to further support (online for those that don’t have time, structured education for those that do, but struggle with tech and language)

### Understanding what diabetes is and its’ causes

<b>Barriers</b>	<b>Facilitators</b>	<b>BCTs/Strategies</b>
Lack of understanding about diabetes prevention (6) and management (12)	Some understanding that diabetes due to diet (and stress) and not eating healthily	Accessible explanation of causes of diabetes and pre-diabetes (illness perceptions), influence understanding of consequences and management, information about health and emotional consequences of not changing
-humoral imbalance theory of health (6), especially with older adults (12)	Willingness to engage to increase knowledge (3, 14, 17)	
-Normal part of ageing (3)	Little use of herbal	Changing attribution and locus of

	medicine to treat diabetes (3%), much higher use of Western medicine (17)	control from external to internal-increase personal and treatment control, by creating cognitive dissonance between past behaviour (working hard to increase economic security) and current beliefs about health (fatalism)
-What is pre-diabetes (4)		As above.
-over-eating leading to infection (18)		Practical instruction on ways that behaviour can be changed (substituted) whilst minimising impact on social identity.
-Fatalism– diabetes due to God's' will/ <i>kismet</i> (6, 16, 18, 20)	BUT also taught to live differently and take care of self (16, 18, 3)	
-diabetes due to pollution	Spiritual and physical discipline (3)	Increasing optimism, that can live well with diabetes if managed well, contrasting outcomes here with India, where incidence of T2DM and outcomes often poorer, to challenge idea that lack opportunity and out of control (comparison of future outcomes here and in India/Pakistan)
Externalising attribution -weather (20)	Illness perceived as sign that God is not pleased and something needs to change (6)	
-Stress (6)		
-heredity (6)		
Diabetes causing an irreversible decline (20)		
Reluctance to change beliefs/behaviour (6, 16)		Act as role model for younger generation (collectivist thinking, anticipated regret of not changing behaviour), contrast with previous actions taken to improve QOL for self and loved ones when little support from wider society (cognitive dissonance)
Appearing larger weight is attractive as sign of wealth and health (6) (this necessarily true?)		(Beliefs changing as food abundant)
Doctors seen as having complete understanding of individuals' health issues and primarily responsible for managing diabetes (6)	Doctors knowledgeable so should follow advice (6, 16)	Challenge belief – doctors little contact (up to an hour every few months for most people, if not less than 10 minutes for regular check up, even if every 6 months, how meant to know what patients doing for other 4380 hours of their lives, especially with how many people they see?). Not that they are not knowledgeable about diabetes, but cannot expect them to be informed on every decision made. Reflect on and question this belief. Motivate need to see

		how can apply advice to own life.
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### Increasing physical activity

<b>Barriers</b>	<b>Facilitators</b>	<b>BCTs/Strategies</b>
Cold weather (1, 2, 20) – walking in cold means that some people would eat warm food in order to ‘counteract’ cold (2). Belief that can cause indigestion and slowed metabolism (16)	Walking acceptable for women, but not too quickly in public, especially in groups (3); as is exercise with family or at home (1); indoor exercise bike/treadmill being available (20); doing exercise as part of daily chores or when helping the family (20); being active as part of praying movements – limit to this though (20)	Culturally appropriate behaviour substitution when walking in the cold (drinking warm water with lemon commonly believed to be healthy and natural remedy for general malaise). Culturally appropriate activities suggested (how to instructions) that can incorporate into routine with less cognitive effort, encourage healthy habit formation.
Gym/swimming pool ‘for English’ (1,2), lack of culturally sensitive (e.g. women-only) facilities, concerns about exercising with others in own community and being ‘gossiped about’ (20)	Team sports favoured activity for men – especially Kabbadi, though in football not always easily accepted by other people (2)	Engendering positive social support, collective efficacy. Drawing on past behaviour when has been healthy, as may influence future behaviour.
Time, cost, childcare, personal safety (including racism), working long hours in physically demanding jobs (men particularly, 1, 2, 6, 20) or anti-social hours (20)	Dancing socially acceptable and encouraged for women (15)	Encourage participation in culturally acceptable activities and signpost to activities that can expand on this. Free/low cost resources where possible, as well as classes. Encouraging planning ahead when involves changes in routine and structured activity
Exercise for personal reasons ‘selfish’, duty first to family/community (6, 20)	Simple education about physical activity (4), including examples of activities that will burn 100kcal, 200kcal, 300kcal (3)	How to instructions, concrete – examples with calories burned to help behavioural self-monitoring and goal setting.
Misunderstanding about value of PA in diabetes prevention and management, or belief that it may weaken person (6) or body cannot support it (20); anxiety about bodily sensations accompanying PA (moderate-vigorous	Prioritising short term goals e.g. not wanting to move onto injecting insulin (20), seeing blood sugars immediately decrease as a result (20)	Address belief – education (challenge illness perception – link to management and cause of diabetes, coherent model of illness and treatment), address anxieties about physiological sensation to alleviate distress.

particularly) as a result (20)		
Women – do not think that vigorous exercise is socially acceptable as may be for misperceived reasons (i.e. thinking it is out of economic/social necessity – i.e. family letting them down as they have a car but they are walking to get things done – rather than for physical benefit (20), not socially acceptable as will become sweaty; immodest, when walking must be seen not to hurry (6)		Engendering social support, encouraging to get involved, see as role models for younger family members or follow role models available – challenging idea that will always perceived as negative.
Co-morbidities – e.g. arthritis, cardiovascular disease, after having a stroke (20)		Instructed to check with doctor before taking new activities.

### Changing diet

<b>Barriers</b>	<b>Facilitators</b>	<b>BCTs/strategies</b>
Confusion between ‘diet’ and ‘dieting’ therefore eating the same types of food but in smaller quantities or at night as soon as blood sugar reduced enough (20)	Culturally appropriate substitutions for unhealthy ingredients (booklets and leaflets, 11)	Address confusion between diet and dieting, instructions on substituting ingredients in food (culturally appropriate manner)
Asian foods ‘bad’, Western foods ‘good’ (20, 13)	Cooking differently to benefit entire family (2)	Self-monitoring current behaviour, reversing habit (e.g. amount of oil used in cooking).
Dieticians recommendations culturally inappropriate (1) as Asian food a part of social and cultural life (1)	Can give healthy snacks instead of samosas et al as hospitality (e.g. fruit and juice, 11)	Information about antecedents (i.e. being present at social gatherings where unhealthy food is provided) and engendering social support/collective efficacy as problem solving.
-Hospitality (20) – giving generous portions of food and having to eat it (6, 20)	Managing portion sizes of food consumed, especially in Gurdwara if visit a few times a day (3, 17)	Problem solving/ general goal setting – portion control.
-Wealth, status (6, 11) – certain foods which thought of as ‘traditional’ but these were rare in	Highlighting positives in Punjabi diet (e.g. plenty of fruit and veg, wholemeal flour in rotis, 3)	Creating cognitive dissonance between beliefs about what is considered traditional in the Punjabi diet and what actually

India (e.g. butter, ghee, full cream milk, samosas, sweets) – these foods given special status and they may be familiar, evocative of good memories (eaten 2-3 x/year) (6, 11, 12, 17), but common here (11, 17)		was routinely consumed, highlight those aspects which are healthy and actually traditional. Food (behaviour) substitution. Build up substitutions (graded tasks).
	Reading nutritional labels (3)	
	Punjabi version of eat well plate (3)	
-Misconception that full-fat milk is only source of fat in diet, despite what doctors say (17) -cooking with oil, frying, sugary (also seen as more attractive)	Western medicine compatible with Sikhi, should use advice and help to have healthy body (17)	
-Bonding with children/grandchildren through ‘traditional’ foods – bringing heritage to them (2)		Challenge belief
-Place in community functions (2)		Creating cognitive dissonance – debunking notions of what is traditional (and weakening link with identity), and creating tension between desire to take care of children/grandchildren as strong cultural mandate, and actual behaviour
Women – in Canada – incorporating all of family’s preferences into shopping and cooking out of love (13), including relatives when they visit (1) (although latter based on assumptions of what they would expect?)		Problem-solving – eating more mindfully, paying attention to satiety, distractions through dancing and socialising (coping planning)
Acculturation leading to greater consumption of convenience foods, sweets, soft drinks, eating out, red meat (15)	But also trying to balance with being healthy (13)	Challenging assumptions about what relatives might want, and instructions on how to change what offered in culturally appropriate manner
Older (and some middle-aged) adults perceiving immediate relationship between food intake and health impact on body	But also greater consumption of healthy foods, fruit and veg (as more accessible and read nutritional value of food)	Healthier convenience options

(e.g. if experiencing ‘bai’ – indigestion, unsettled, wind – then need to eat certain foods straight away to balance out, pinni ‘good for memory’) (13)	and low fat foods, more choice. More stir-frying, BBQing, less deep fat frying (15)	
Older (and some middle-aged) adults perceiving immediate relationship between food intake and health impact on body (e.g. if experiencing ‘bai’ – indigestion, unsettled, wind – then need to eat certain foods straight away to balance out, pinni ‘good for memory’) (13) Healthier diet is perceived as moving toward a ‘Western’ diet, regarded as ‘bland’, ‘tasteless’ (20)	Middle-aged adults mixed and matched humoral theory of health with ‘Western’ model, see nutrition and physical activity as having a long term impact on health (13) Picked up some health knowledge from the media (15)	Illness cognitions – understanding of causes and consequences of disease (long term timeline, more coherent model of health and diabetes)
Alcohol at weddings – open bar, alcohol problems taboo subject (13; 17)		Culturally appropriate suggestions for cooking
Unhealthy eating at Ramadan or participating when not medically fit to do so (also skipping medication)		Acknowledging issue compassionately; health consequences for diabetes; instructions how to manage use and suggestion of socially acceptable alternatives; signposting for further support
	Islam allows those who have health problems to not fast, or do so later in the year, about discipline-can have healthy foods (and change medication times)	Signpost to guidance by Muslim council of Britain and Diabetes UK

### Oral medication

Necessity	Concerns	BCTs/strategies
Effective to cure/control diabetes (7; 18), former associated with having less education than latter.	Allopathic meds generally – chemicals present (10)	Adherence high so not necessary

Homeopathic remedies may cure/control diabetes, particularly ‘natural’, food-based remedies (but taken alongside rather than <i>instead of</i> allopathic medicine) (10)		
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### Alternative therapies

Necessity	Concern	BCTs/strategies
Varying level of belief in ability to control diabetes – uptake can be low (3% in 18)	Low concern as ‘natural’ and ‘established’ remedies for many years – particularly for karella (10)	Challenging taken-for-granted belief that does not have consequences (e.g. interacting with meds), affirm that research being done into vegetable that close cousin to karalla
Belief that may reduce/regulate blood sugar (10)		Question this, and compare outcome if it does work this way, versus via slow increases in blood sugar levels as both are different
Belief that may cure diabetes (10)		Re-state that no known cure for diabetes

### Insulin injections uptake

Barriers	Facilitators	BCTs/Strategies
Belief that insulin may make diabetes worse, or that diabetes can be cured with ‘a couple of tablets’ (7)	Understanding the purpose of insulin and what it does, through accessible analogy (9)	Increasing illness understanding and how it is controllable through treatment
Psychological insulin resistance – certain aspects of this may be accentuated in South Asians (7)		
-Perceived personal failure and self-blame (7)	Responding to caring and compassionate GP who persistent in trying to help (8)	Addressing stigma and blame culture in community, linking to distress and poor self-care (coping with illness) – emotional and health consequences, reframing behaviour by those in wider community

-Concerns about weight gain (7)	Addressing misconceptions (9)	Addressing concerns about insulin
-Fear of injections (7, 8)	-e.g. showing new pen injection devices to address fear of injections (9)	-Information about new pen injector devices and where to get further support (problem-solving)
-Hypos (7, 9)	Showing that going onto insulin in timely way to prevent or delay complications and damage by diabetes before diagnosis when they might have been asymptomatic (7)	
South Asians influenced more greatly by negative perceptions of others about insulin injections (7, 8, 9)	Involving peers and family in making the decision to move onto insulin injections (7, 8)	Engendering social support, those taking insulin role models for those who may need to take it in future
social stigma (8, 21)	Seeing peers or family on insulin – sense of resignation (7, 8, 13)	
-concerns about privacy in doing injections (8)		Education about new pen devices, discretion
-association between insulin and severity of T2DM, including complications (8)		Addressing link between poorly controlled diabetes and outcome for treatment (illness perceptions)
-Blame by others for ‘failing’ to control it through diet and/or oral medication alone, especially so from family elders (7, 8, 13)		Engendering positive social support (emotional)
Concerns that insulin from animal sources (8)		Address misconception
Belief that insulin is the ‘last resort’ and that should control it via diet and/or oral medication (8)		Reframing it as something to move onto in timely way (not discouraging lifestyle changes, as these are positive), to enhance perceptions of treatment control
The referral pathway has delays built in, accentuated by the delays built into the system as may meet several health professionals in the care pathway and use this to re-negotiate insulin use with those professionals, therefore increasing		

delays; especially so with 'patient empowerment' model (7)		
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## **Studies:**

### **Pre-diabetes**

- 1) Cross-Bardell (2015)
- 2) Morrison (2014)
- 3) Islam (2014)
- 4) Khunti (2010)

### **Diabetes**

- 5) Ivey (2004)
- 6) Lucas (2013)
- 7) Patel, Naina (2012)
- 8) Patel, Naina (2015a)
- 9) Patel Naina (2015b)
- 10) Patel, Neesha (2015)
- 11) Wallia (2013)

### **Other relevant studies**

- 12) Azar (2013)
- 13) Chapman (2011)
- 14) Walker (2015)
- 15) Lesser (2014)
- 16) Jepson (2012)
- 17) Oliffe (2010)
- 18) Sandhu (2005)
- 19) Labun (2007)
- 20) Lawton (2008)
- 21) Lawton (2006)

# Appendix D: Evaluations by client (radio producer) and radio presenter

## Radio Producer

**Feedback Form: Radio Producer**

1. Was the content of the radio talks easy to understand for the audience?

1	2	3	4	5	6	7	8	9	10
Not at all									Very well

2. Were the causes, symptoms and treatment of type 2 diabetes explained clearly?

1	2	3	4	5	6	7	8	9	10
Not at all									Very well

3. Did the talks address the topic of coping with diabetes well?

1	2	3	4	5	6	7	8	9	10
Not at all									Very well

4. Was the content appropriately tailored to a Punjabi listening audience?

1	2	3	4	5	6	7	8	9	10
Not at all									Very well

5. Did the work fulfill the aims set out at the start of the consultancy (to address diabetes from a psychological perspective)?

1	2	3	4	5	6	7	8	9	10
Not at all									Very well

6. Was it carried out to a professional standard?

1	2	3	4	5	6	7	8	9	10
Not at all									Very well

7. Were they delivered within a good timeframe?

1	2	3	4	5	6	7	8	9	10
Not at all									Very well

8. If you have any other feedback, please leave below.

lot of commitment + energy. big challenge but you handled it.

**Radio presenter**

**Feedback form 1 – Desi Radio talk**

6. How well did you think the audience understood the talks?

1	2	3	4	5	6	7	8	<b>9</b>	10
Not at all									Very well

1. How well did you understand the causes of diabetes before the talks?

1	2	3	4	5	6	7	8	<b>9</b>	10
Not at all									Very well

(please circle your answer)

2. How well did you understand the causes of diabetes after the talks?

1	2	3	4	5	6	7	8	<b>9</b>	<b>10</b>
Not at all									Very well

3. How well did you understand what helps people cope with diabetes before the talks?

1	2	3	4	5	6	<b>7</b>	8	9	10
Not at all									Very well

4. How well did you understand what helps people cope with diabetes after the talks?

1	2	3	4	5	6	7	8	<b>9</b>	10
Not at all									Very well

5. How well did you think the talks addressed the topic of making lifestyle changes for diabetes prevention and management (i.e. diet, exercise, alcohol, fasting)?

1	2	3	4	5	6	7	<b>8</b>	9	10
Not at all									Very well

Kashmiri Panna  
KkPanna  
Presenter at Desi Radio

6. How well do you think the talks addressed the topic of medication and insulin use for diabetes management?

1	2	3	4	5	6	7	8	9	10
Not at all								Very well	

7. How well do you think the talks related to the audience overall?

1	2	3	4	5	6	7	8	9	10
Not at all								Very well	

8. How well do you think the audience understood the talks?

1	2	3	4	5	6	7	8	9	10
Not at all								Very well	

9. Positive feedback from audience (comments)

Few people called back to say that Kiran tried very hard to explain in details but Punjabi being 2nd language, she did very well.

10. Negative feedback from audience (comments)

Little bit struggled with Punjabi

11. Anything else you think I did well?

Found Kiran very relaxed and pleasant while doing interview

12. Anything else you think I can do better?

Learn more Punjabi

Kashmir Panne  
KkPanne  
Presenter at Dosi Radio

## UNIT 3: BEHAVIOUR CHANGE INTERVENTION

### **Behaviour change intervention case study: Using a Social Cognitive Theory based approach to promote healthy eating for a group of adults with mild learning disabilities**

#### **Background**

Part of the role of a trainee health psychologist in ██████████ involved providing health promotion support to adults with learning disabilities through workshops with service users and staff in the organisation. ██████████ provided social care services to adults with learning disabilities in residential care homes, supported living projects and outreach services. After a staff training session was delivered, a manager requested support to promote healthier eating effectively to a client whose poor diet they were particularly concerned about within a supported living context. Following an initial discussion, assessments were arranged for several clients in this home to determine their support needs and whether a health promotion programme or onward referral to specialist services could benefit them as appropriate.

Before intervention development and planning began, a literature review was conducted on the topic. This suggested adults with mild-moderate learning disabilities often have poorer diets than those in the general population (Dunkley, Tyrer, Gray et al., 2017; Emerson et al., 2016; Hsieh et al., 2014). This was due to greater independence in decision making and reduced support provision relative to those with more severe learning disabilities, combined with physical and cognitive impairments limiting access to traditional health promotion initiatives (Bergström et al., 2014).

Previous research also indicated health promotion interventions aimed at improving understanding benefits of healthy eating and how this could be applied in their own lives, in a mutually supportive environment, could help participants improve their diets (Bergström et al., 2014; Melville et al., 2011), though this did not sometimes does not work better than a 'placebo' group intervention (McDermott et al., 2012). This may be because social support could have been the key driver for improved diet in McDermott et al. (2012) or changes in self-efficacy were measured but they did not aim to increase this in the intervention because it can be difficult (Conner & Norman, 2015; Willems et al., 2017). Thus, interview research

was carried out with adults with learning disabilities and carers using a Social Cognitive Theory-based approach (Bandura, 1986; Bandura, 2001).

The findings informed the needs assessment for clients, including development of measures tailored to adults with learning disabilities where appropriate. These covered knowledge, outcome expectancies, self-efficacy, social support, level of learning disability, challenging behaviour and subjective well-being. The intervention was then developed and piloted with service users attending an outreach service and content subsequently changed following feedback and prior experience, for delivery in supported living services in the organisation. This was the third iteration of the group intervention.

## **Methods**

Seven service users demonstrated interest in attending and were assessed for inclusion in the group intervention (see Appendix A for the needs assessment of this group and practice log for the intervention plan, session plans and materials). Six were assessed as having enough understanding of what was involved to participate in the intervention. This was based on their scores on a brief learning disability severity screening measure, engagement with outcome measures and ability to verbally communicate their understanding of what the intervention focussed upon when this was probed during the assessment process as appropriate. For example, they were asked to explain briefly what topics the intervention would be focussing on, which was mainly healthy eating, though they were given some flexibility, such as by stating it was about *'being healthy'*.

Outcomes measures focussed on healthy eating knowledge, outcome expectancies regarding healthy eating and cooking, self-efficacy, social support from staff and peers, quality of life, subjective wellbeing and self-reported healthy eating and physical activity logs in a pre-post intervention design. Within-subjects inferential tests were not conducted due to the very small sample size for comparison but changes in mean score were considered for those who completed pre and post outcome measures (5 participants).

Additional baseline measures assessed challenging behaviour and level of learning disability. These were used to screen for eligibility for group intervention and plan the delivery process, for example guiding behaviour management of service users where appropriate. Referral processes were also set up at this stage to staff and other services in the event of any health or safeguarding concerns that could arise during intervention delivery.

There were seven group intervention sessions and all participants attended five or more workshops. Reasons for non-attendance were attending other health appointments or being at work at times which clashed with the session. Users were also offered additional one to one support to set and meet individual goals as previous research suggested this could help some clients change their behaviour (Melville et al., 2011). There were no drop outs for this intervention.

The intervention was overseen by the workplace contact, a clinical psychologist providing learning disability services in this borough (see appendix B for the supervision plan).

### **Intervention aims and structure**

The sessions aimed, firstly, to improve clients' knowledge and outcome expectancies of healthy eating, physical activity and sedentary behaviour by presenting benefits of healthy eating and helping service users make palatable food to taste. Secondly, to help them develop their sense of self-efficacy, service users were taught examples of how they could put this teaching into practice through preparing and cooking food at the end of every session with simple dishes that used ingredients and food categories discussed earlier in the workshop. They were also given recognition and praise for their efforts, help to develop their skills and knowledge and engage with behaviour change. Clients were also provided with opportunities to set individual, realistic goals, to assist them in making health-promoting lifestyle changes.

Additionally, support staff were present in sessions, had opportunities to ask questions and given copies of handouts to aid provision of informed practical and emotional support. They were also offered a separate education session to explore their role in promoting health with clients as they supported them emotionally and practically, sometimes acting as proxy decision makers due to limitations in some clients' cognitive and physical abilities. This aimed to build their sense of proxy efficacy (Bandura, 2001), but they were not able to make use of this opportunity due to staff shortages. Finally, service users were also helped to give each other mutual encouragement and support to engage in health promoting behaviour within their abilities and understanding. The group intervention took place over seven weekly sessions and each session lasted approximately two hours, with additional 1-1 support where appropriate and desired by service users. These were led by the trainee health psychologist and co-facilitated by a volunteer. Baseline and follow up assessments were also conducted with clients, which informed sharing of progress reports with the manager of the service.

## **Workshop content**

The initial session focussed on tangible benefits of eating healthily including positive effects on mood, strength and bone density. Participants matched healthy foods to what they thought were their benefits. Improved knowledge and positive outcome expectancies of healthy eating were sought (Bandura, 1986; Bandura, 2001). The importance of sufficient fruit and vegetable intake was emphasised, particularly the latter. At the end of the session service users were taught to make healthy wraps with salad and vegetables as this was accessible and involved little preparation of ingredients, aiming to act as a healthy replacement for sandwiches at lunchtime. The sessions took familiar dishes and aimed to show participants how they could be made healthier as earlier research suggested this was within their '*comfort zone*' and therefore easier to trust than food that were completely novel and unfamiliar. This also facilitated gradual adaptation of food intake, something carers in the research study suggested was important for initiating and sustaining behaviour change.

The second session then focussed on intangible benefits of healthy eating, covering benefits of sufficient iron and fibre intake, and time was spent preparing materials so that these could be presented more experientially for service users. To do this, the impact of iron intake on reducing fatigue associated with anaemia was explained, as a previous iteration suggested visually presenting red blood cells was too abstract for service users to understand and put into context for their health. The impact of fibre intake on reducing constipation was also described, as previous research suggests this can be more prevalent for adults with Downs' syndrome and moderate to severe learning disabilities (Böhmer et al., 2001; Wallace, 2007). This applied to some service users living in this context supported by staff, including those that attended healthy eating workshops.

In the first session it was observed that several learners struggled to sort sixteen individual food items into five potential benefits with support. In subsequent sessions task choices were simplified further for this group. This was achieved by presenting a dichotomy between a pictorial list of items that would be helpful for increasing fibre intake, for example, versus those that would not. Learners were much better able to engage with the task when faced with a single choice. However, for future iterations it became apparent that a new set of items that would enable service users to only increase their iron intake would be needed as some provide this as well as fibre, because this was confusing for some service users. Those that provide iron and fibre could be represented separately, allowing reinforcement of the idea

some foods have several health promoting benefits, but service users do not need to eat twice as much to obtain both of these. This is because portion control was still important, particularly regarding fruit intake due to high sugar content.

The following session concentrated on applying learning to practice as we focussed on making familiar meals in a healthier manner. Service users also shared their meal preferences to inform individual goal setting sessions. Individual healthy pizzas were then made as this enabled provision of one-to-one support with service users. As done previously, several ingredients which had been discussed in the education session were used in cooking and participants were questioned on their individual benefits, with reminders where appropriate. However, due to limited facilities, the session was lengthier and it was more challenging to keep individuals engaged as each person had periods of inactivity due to need for supervision during preparation and cooking. The co-facilitator was also not available, so this was a session I ran with very little support, making it more difficult to manage. Nevertheless, service users engaged well when cooking under supervision, and more generally, responded well to tactile objects in education sessions, so these were included in the intervention protocol for future teaching.

Healthy eating was not discussed in context of weight control, as interview data from the research study indicated people with learning disabilities were already very aware of their association. This could also sometimes be the focus of educating certain clients to detriment of those who were not perceived to have a '*weight problem*' though they may need just as much support, whilst other benefits of healthy eating would often get overlooked (O'Leary et al., 2018). It could also lead to shame and feelings of inadequacy, which is implicated in disordered eating behaviour in adults in the general population and those with a history of eating disorders (Kenneth & Steven, 2009; Troop, Sotrilli, Serpell, & Treasure, 2006). Additionally, when conducting assessments, one client was observed to have eaten two chocolate bars and apparently hid this behaviour from support staff. This was a service user whose diet they were particularly concerned about. This indicated the individual was concerned about censure and the workshops aimed to address this through building trust, rapport and encouraging and praising engagement with health promoting behaviour rather than punishing non-compliance (Bandura, 1986).

Additionally, to meet the needs of these sorts of individuals more effectively, content included materials to educate service users on the need for moderating fat and sugar intake. This included limiting juice and reframing this as an indulgence and demonstrating how they could make healthier versions of 'treats'. This aimed to build on teaching how they could include more vegetables and wholegrains in their diet, to using root vegetables such as sweet potato or carrots in drinks and dessert. However, a balance was struck between educating users on what was needed for an ideal diet, particularly focussing on increasing vegetable intake and being realistic to minimise risk of setting up service users for failure (Bandura, 1986). Thus, some items made still had significant sugar content and they were informed of this to discourage over-indulgence, but this was balanced with having a compassionate and accepting approach.

Encouraging compassion for themselves and each other may be particularly important in alleviating shame, self-criticism and disordered eating (Steindl, Buchanan, Goss, & Allan, 2017). This was achieved by acknowledging that enjoyment of food was important to clients and that this was acceptable, showing compassion and acceptance as a role model (Bandura, 1986), and fostering relational trust and rapport with them as a group to help create a sense of safety (Steindl et al., 2017). This was also a key part of educating staff present, as they were previously unaware of this. This also applied when doing a session on choosing healthier options when eating out and having takeaways. Availability and affordability was an important consideration when making recommendations and some options in the local environment met these criteria, but this was a weekly indulgence. This was approached carefully with service users as sustaining self-regulation can be cognitively effortful, to avoid being excessively restrictive and cause disengagement (Bandura, 1986). This was especially important amongst a cohort with limitations in ability and for those that may struggle with impulse control (Smyth & Bell, 2006). Thus, being realistic about what can be achievable is also important, particularly for adults with learning disabilities. They may struggle to accurately appraise how successful their endeavours are likely to be due, firstly, to difficulties in self-awareness and secondly, being conscious of scrutiny by carers in their daily lives (Bandura, 1986; Trip, Conder, Hale, & Whitehead, 2016). Thus, it was important to minimise distress and discouragement from repeated failure (Bandura, 1986) and this was also important for goal setting sessions with individual clients.

Content was included on the benefits of increasing physical activity in one session to improve service users' outcome expectancies and motivate engagement to participate in this for their health. To address practicalities of implementing this in practice with this group, recommendations were adapted to take the limited mobility of some users into consideration. This was done by including material on benefits of muscle strength exercises, such as weight training, for cardiovascular health (Loprinzi et al., 2017) and material on light exercise. Walking was particularly encouraged as this is inexpensive, relatively accessible and an activity most adults with learning disabilities do at least some of their time (Dunkley, Tyrer, Gray et al., 2017; Melville et al., 2015), though Melville et al. (2015) also suggested promoting home-based activities as this may prompt greater uptake. Research undertaken with learning disabilities prior to the intervention also suggested some adults with learning disabilities liked to do functional exercise as they saw it as more purposeful than recreational physical activity. Thus, I included examples of activities for both outcomes, such as walking to local shops, housework and gardening to improve their home environment.

Service users were also educated on the benefits of reducing sedentary behaviour and practical ways they could achieve this (e.g. standing when doing chores, chair-based exercises). This was useful as it could be more accessible for those with low mobility and this can be highly prevalent in adults with learning disabilities (Melville et al., 2017), so teaching was more inclusive and relevant for attendees of this workshop. Service users also had the option of being referred to the [Opening Doors] project if they wanted to access opportunities for recreational physical activity, including museum visits and exercise classes. Finally, service users and staff were given an exercise DVD recommendation which users with learning disabilities of previous community-based intervention had found this useful and accessible, including those with low mobility (Association for Real Change, 2013).

Finally, I aimed to increase positive social support behaviours amongst service users and as peer influences could have significant impact on behaviour (Bandura, 1986; Bandura, 2001; Kuijken, Naaldenberg, Nijhuis-van der Sanden & van Schrojenstein-Lantman de Valk, 2016). It was noted, at times, in earlier workshops, this was present and service users were given recognition for this. Role play was also used to explore what could be helpful, and what would not. This focussed on use of praise and encouragement, sharing information and reminders, or cooking together if they were able to do so. However, service users were also taught it was acceptable to ask staff for help in this regard as some may have social

difficulties or find it problematic to establish boundaries if peers began to display demanding behaviour (Tyrer, Nagar, Evans, Oliver, Bassett, Liedtka et al., 2016).

### **Delivering the intervention**

Participants engaged well with activities overall and attendance was fairly consistent amongst sessions. One service user who initially did not participate in any cooking, began to do so after four weeks, and had shown curiosity about the pizzas cooked in the previous session as he had wanted to see what had been produced. Service users also aimed to support each other and sampled foods they prepared and cooked with enthusiasm, some which they reported not having previously tried. The sessions were flexible about how they proceeded and activities were treated as optional according to priorities of the users and how they responded to what was happening (the '*situation back talk*', Schön, 1983). Staff also aimed to attend sessions, but this was not always possible due to other responsibilities, so delivering feedback reports on sessions to the manager was also helpful. It was hoped they could implement changes between sessions and monitor involvement, to build on what had been covered in the workshops, but this was inconsistent.

### **Results and assessment process**

None of the outcomes changed statistically significantly (see Appendix C for full results pre-post intervention). At least one person became aware that healthy eating could benefit people generally, not just those with weight concerns or pre-existing medical conditions. Outcome expectancies apparently improved for some users to a very small extent (mean score of 3 at baseline versus 3.6 at follow up), though two users did not give both pre and post-intervention scores due to issues with understanding of the self-report measures in the assessment, which can vary in this population so were excluded from analyses. However, though the programme aimed to assess food and physical activity intake at baseline, most service users did not complete these. In future, if consented to by participants, staff would be asked to record this in daily logs, so these could be transferred to the measure by the intervention lead. Subjective wellbeing at baseline was high and this remained the case at post intervention assessment. Knowledge increased during sessions but was not retained at the end of the workshops, so service users may need reinforcement of information by staff on an ongoing basis to retain this. This was a recommendation made to the manager at the end of the intervention (also see Appendix D for further reflections on delivering the intervention).

## References

- Association for Real Change (2013), *Take the Health Challenge Report*. Association for Real Change Cymru, UK. Last retrieved 11.06.18 from <http://arcuk.org.uk/wp-content/uploads/2013/05/Take-the-Health-Challenge-Project-report.pdf>
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, N.J: Prentice-Hall.
- Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, 52(1), 1-26. 10.1146/annurev.psych.52.1.1.
- Bergström, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities-a qualitative study. *Health Education Research*, 29(2), 259-271. 10.1093/her/cyt111
- Böhmer, C. J. M., Taminiau, J A J M, Klinkenberg-Knol, E. C., & Meuwissen, S. G. M. (2001). The prevalence of constipation in institutionalized people with intellectual disability. *Journal of Intellectual Disability Research*, 45(3), 212-218. 10.1046/j.1365-2788.2001.00300.x. Retrieved from <http://dx.doi.org/10.1046/j.1365-2788.2001.00300.x>
- Conner, M., & Norman, P., (2015). *Predicting and changing health behaviour: Research and practice with social cognition models* (Third ed.). Maidenhead: Open University Press.
- Dunkley, A. J., Tyrer, F., Gray, L. J., Bhaumik, S., Spong, R., Chudasama, Y. et al. (2017). Type 2 diabetes and glucose intolerance in a population with intellectual disabilities: The STOP diabetes cross-sectional screening study. *Journal of Intellectual Disability Research*, 61(7), 668-681. 10.1111/jir.12380 Retrieved from <http://dx.doi.org/10.1111/jir.12380>
- Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2016). The physical health of british adults with intellectual disability: Cross sectional study. *International Journal for Equity in Health*, 15, 11. 10.1186/s12939-016-0296-x

- Hsieh, K., Rimmer, J. H., & Heller, T. (2014). Obesity and associated factors in adults with intellectual disability. *Journal of Intellectual Disability Research*, 58(9), 851-863. 10.1111/jir.12100. Retrieved from <http://dx.doi.org/10.1111/jir.12100>
- Kenneth, G., & Steven, A. (2009). Shame, pride and eating disorders. *Clinical Psychology & Psychotherapy*, 16(4), 303-316. 10.1002/cpp.627. Retrieved from <https://0-doi-org.wam.city.ac.uk/10.1002/cpp.627>
- Kuijken, N. M. J., Naaldenberg, J., Nijhuis-van der Sanden, & de Valk, van Schroyenstein-Lantman. (2016). Healthy living according to adults with intellectual disabilities: Towards tailoring health promotion initiatives. *Journal of Intellectual Disability Research*, 60(3), 228-241. 10.1111/jir.12243
- Loprinzi, P. D., Addoh, O., & Mann, J. R. (2017). Association between muscle strengthening physical activities and mortality among American adults with mobility limitations. *Preventive Medicine*, 99, 207-210. Retrieved from <http://0-www.sciencedirect.com.wam.city.ac.uk/science/article/pii/S0091743517300610>
- McDermott, S., Whitner, W., Thomas-Koger, M., Mann, J. R., Clarkson, J., Barnes, T. L. et al. (2012). An efficacy trial of 'steps to your health', a health promotion programme for adults with intellectual disability. *Health Education Journal*, 71(3), 278-290. 10.1177/0017896912441240
- Melville, C. A., Boyle, S., Miller, S., Macmillan, S., Penpraze, V., Pert, C. et al. (2011). An open study of the effectiveness of a multi-component weight-loss intervention for adults with intellectual disabilities and obesity. *British Journal of Nutrition*, 105(10), 1553-1562. 10.1017/S0007114510005362
- Melville, C. A., Mitchell, F., Stalker, K., Matthews, L., McConnachie, A., Murray, H. M. et al. (2015). Effectiveness of a walking programme to support adults with intellectual disabilities to increase physical activity: Walk well cluster-randomised controlled trial. *International Journal of Behavioral Nutrition and Physical Activity*, 12, 125. 10.1186/s12966-015-0290-5
- Melville, C. A., Oppewal, A., Schäfer Elinder, L., Freiburger, E., Guerra-Balic, M., Hilgenkamp, T. I. M. et al. (2017). Definitions, measurement and prevalence of

sedentary behaviour in adults with intellectual disabilities — A systematic review. *Preventive Medicine*, 97, 62-71. Retrieved from <http://0-www.sciencedirect.com.wam.city.ac.uk/science/article/pii/S0091743516304534>

O'Leary, L., Taggart, L., & Cousins, W. (2018). Healthy lifestyle behaviours for people with intellectual disabilities: An exploration of organizational barriers and enablers. *Journal of Applied Research in Intellectual Disabilities*, 31, 122-135. 10.1111/jar.12396

Patel, N., Stone, M. A., Hadjiconstantinou, M., Hiles, S., Troughton, J., Martin-Stacey, L. et al (2015), Using an interactive DVD about Type 2 Diabetes and Insulin Therapy in a UK South Asian community and in Patient Education and Healthcare Provider Training, *Patient Education and Counselling*, 98(9), 1123-1130.

Schön, D. A. (1983). *The reflective practitioner: How professionals think in action*. New York: Basic Books.

Smyth, C. M., & Bell, D. (2006). From biscuits to boyfriends: The ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*, 34(4), 227-236. 10.1111/j.1468-3156.2006.00402.x. Retrieved from <http://dx.doi.org/10.1111/j.1468-3156.2006.00402.x>

Steindl, S. R., Buchanan, K., Goss, K., & Allan, S. (2017). Compassion focused therapy for eating disorders: A qualitative review and recommendations for further applications. *Clinical Psychologist*, 21(2), 62-73. 10.1111/cp.12126

Thagard, P. (1989), Explanatory Coherence, *Behavioral and Brain Sciences*, 12(3), 435-467.

Trip, H., Conder, J., Hale, L., & Whitehead, L. (2016). The role of key workers in supporting people with intellectual disability in the self-management of their diabetes: A qualitative New Zealand study. *Health & Social Care in the Community*, 24(6), 789-798. 10.1111/hsc.12262 Retrieved from <http://dx.doi.org/10.1111/hsc.12262>

Troop, N. A., Sottrilli, S., Serpell, L., & Treasure, J. L. (2006). Establishing a useful distinction between current and anticipated bodily shame in eating disorders. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity*, 11(2), 83-90. 10.1007/BF03327756. Retrieved from <https://doi.org/10.1007/BF03327756>

Tyrer, P., Nagar, J., Evans, R., Oliver, P., Bassett, P., Liedtka, N., & Tarabi, A. (2016). The problem behaviour checklist: Short scale to assess challenging behaviours. *BJPsych Open*, 2(1), 45-49. 10.1192/bjpo.bp.115.002360. Retrieved from <https://www.cambridge.org/core/article/problem-behaviour-checklist-short-scale-to-assess-challenging-behaviours/BF120C3FA9E6F3BD98F0B85634E62406>

Wallace, R. A. (2007). Clinical audit of gastrointestinal conditions occurring among adults with down syndrome attending a specialist clinic. *Journal of Intellectual & Developmental Disability*, 32(1), 45-50. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=106133449&site=ehost-live>

Willems, M., Hilgenkamp, T. I. M., Havik, E., Waning, A., & Melville, C. A. (2017). Use of behaviour change techniques in lifestyle change interventions for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, 60, 256-268. 10.1016/j.ridd.2016.10.008

## **Appendix A: Needs assessment (anonymised)**

The understanding of participants regarding healthy eating varied significantly, as did their engagement. One potential learner had insufficient understanding to participate in the workshops. Participants generally were unaware that fruit has high sugar content, so may need some input to change this perception, though past interventions have suggested this can be difficult to achieve for most learners. Thus, education may be needed to reinforce this and staff may also need a session to become aware of this issue so they also reinforce learning. Previous research also suggests adults with learning disabilities sometimes struggle to remember the rationale for changing behaviour, so teaching them *what* they should aim to change may be more effective than *why* (e.g. aiming for 5 veg – particularly greens - and 2 fruit a day, limiting juice intake).

Most learners appeared interested in engaging with this in the interests of losing weight and seemed to think people only needed to eat healthily to lose weight or if they had an underlying condition. Staff also thought certain users needed sessions more than others due to weight issues. Therefore, learners may need some education sessions on the other benefits of healthy eating in an inclusive manner, and this may need reinforcement over several sessions. In the staff session, we will need to emphasise the inclusive nature of promoting healthy eating for service users to engender a culture change. Some learners find it difficult to control their impulses regarding unhealthy eating, particularly snacking, so may benefit from being taught healthier snack alternatives that can be made or bought, as well as to reinforce messages about managing portion sizes as these may still have sugar in them. Likewise, they may need to have education about healthier takeaway options as they have this once a week and some go out to eat alone.

The interventions aim to change outcome expectancies about healthy eating through promoting its' benefits and helping learners to try palatable alternatives to familiar foods. Participants will have opportunities to improve self-efficacy through improving knowledge on how to eat more healthily, making healthy versions of familiar foods, encouragement and praising participation and achievements (including small achievements). Seeing pictures of what they have done during sessions – including in the mood board activity – aim to increase this regarding cooking. They will be taught the importance of positive mutual social support in a session. Staff sessions on health promotion will also help service users' proxy efficacy

(in trusting staff to cook healthy food for them at dinner) and gain positive social support from staff.

Thus, this intervention will be based on Social Cognitive Theory (Bandura, 1986; Bandura, 2001).

## Appendix B: Supervision Plan

Trainee: Kiran Bains

Workplace supervisor: Darren Kirby

Workplace Contact: Dr Roman Raczka (Clinical Psychologist)

Activity	Attendees	Date
Past supervisions: Developing and use of measures for interventions; discussing content and adapting to needs of adults with learning disabilities (understanding, engagement)	Roman Raczka, Kate Theodore (ML), Kiran Bains	Various – Nov 2017, Feb-April 2018
Regular first-line supervision – working with service users, engaging staff in interventions; updates on progress	Kiran Bains, Darren Kirby	Monthly (last supervision 09.05.18) + ad hoc in case of need
Catch up	Kiran Bains, Darren Kirby, Roman Raczka	TBA
Providing evidence of planning and implementing evidence and theory based intervention with service user + support worker	Kiran Bains, Roman Raczka	Ongoing (sharing folder with assessments, teaching plans + examples of resources)
Specialist advice regarding engendering positive social support with family/friends when appropriate for service user with complex mental health issues and difficulties maintaining stable relationships (within current skill set)	Kiran Bains, Roman Raczka	June 2018
End of intervention	Kiran Bains	July 2018
Workplace contact report for portfolio	Roman Raczka	July 2018

## Appendix C: Outcome scores

T1 Score												
User no.	What to eat knowledge (out of 8)	Healthy eating benefits (outcome expectancies) + personal relevance (out of 5)	Fast food enjoyment (1-5 - 5 is tasty)	Healthy eating enjoyment (1-5)	Healthy eating/cooking outcome expectancies (out of 10)	Shopping and cooking involvement (0-4)	Social support - friends (0-2)	Social support - staff (0-4)	Role modelling (social influence, 0-4)	EQ-5D (3-15)	Mini-MANS LD (5-45)	Mobility problems
1+	5 (but understanding unclear)	2	4	5	6	4 (with staff help)	1	3	2.5	11	43	Overweight
2	7	2	2	4	5	4 (with staff help)	1	3	2	10	40	Overweight, Knee problems
3	7	4	2	5	8	4 (with staff help)	2	4	4	13	44	
4	6	2	5	5	6	4 (with staff help)	0	4	2	15*	42	
5	4	4	1	1	6	4 (with staff help)	1	3	4	12	40	Hip problem
6+	Insufficient understanding of questions - may benefit from being taught behavioural strategies and ongoing staff support											
7	6 (understanding unclear at	3	4	5	7	2	1	3	4	15	45	

	times)											
<b>Mean</b>	6	3	2.8	4	6.4	3.6	1	3.4	3.2	12.4	42.2	
<b>T2</b>	What to eat knowledge (out of 8)	Healthy eating benefits (outcome expectancies) + personal relevance (out of 5)	Fast food enjoyment (1-5 - 5 is tasty)	Healthy eating enjoyment (1-5)	Healthy eating/cooking outcome expectancies (out of 10)	Shopping and cooking involvement (0-4)	Social support - friends (0-2)	Social support - staff (0-4)	Role modelling (social influence, 0-4)	EQ-5D (3-15)	Mini-MANS LD (5-45)	Mobility problems
<b>1+</b>	Not understood questions (agreeing with everything stated)											
<b>2</b>	6	3	4	5	10	4	1	3	4	11	42	Knee problem
<b>3</b>	6	4	5	5	8	4	2	2	3	15	45	limited mobility (scoliosis)
<b>4</b>	1	3	4	1	5	4	1	4	4	12* (out of 12)	42	
<b>5</b>	5	5	1	1	10	4	1	4	2	10	38	
<b>6+</b>	5	2	Not sure	1	Not sure	1	1	3	4	11	27 (of 30)	
<b>7</b>	6	3	5	5	6	4	1	3	4	15	42	
<b>Mean</b>	2.4	3.6	3.8	3.4	6.8	4	1.2	3.2	3.4	14.8	40.8	

+Excluded from analyses

\*Adjusted score so both evaluated out of 30 proportionally

## **Appendix D: Reflective entries**

### **Exercises to engage participants**

Previous research (McDermott et al., 2012) and my own interview data suggested that it was important for learning approaches to be experiential and ‘*concrete*’ when working with adults with learning disabilities, and plenty of examples ought to be used to convey concepts to this group. The games used to get people thinking about the benefits of healthy eating, for example, aimed to do just this. However, I noted differences in cognitive ability significantly impacted how well participants understood and engaged with tasks, even within groups in the same setting. This has been noted by Bergström et al. (2014) when evaluating success of their intervention. I found that, even in groups, those with moderate learning disabilities struggled to categorise individual foods according to their benefits. However, when these were aggregated into pictorial lists of healthy versus unhealthy foods to make the sorting task easier, service users examined individual items on each list to examine whether they were healthy or not. Perhaps having these picture lists along with stickers to indicate whether individual foods were beneficial, for example in increasing fibre intake, could be more accessible to service users. The other alternative is to present a forced choice alternative for two participants in pairs to decide between two items at a time and for those with greater ability, presenting more choices in the task for them to sort through to maintain their engagement.

I also previously noted that when we discussed negative examples of support, participants struggled to explain what they felt was negative behaviour. Just in case this was to present as an issue I arranged for my colleagues to role play an example of positive social support, and participants engaged well when directly comparing the two. However, learning how to provide positive social support may take ongoing practice and feedback as social situations may be nuanced. This, however, may be resource intensive in terms of staff input and may not be readily available in a social care context. It is also important to engage with staff so they can also provide ongoing support and guidance to service users on how they can help each other. However, staff can also be unintentionally negative in their support strategies and this was noted in sessions, so it is important to address this tactfully with them as part of interventions, though they may not always be available.

### **Being able to deliver all the sessions versus availability**

I previously found that the number of intervention sessions needed to be flexible to accommodate different user group needs regarding understanding, processing and retention of information so had not set this from the outset. However, the manager of the service was surprised that I was going to deliver weekly sessions over time, and I realised it would have been better to send her a list of the proposed workshops and timeframe. She also wanted these to occur every fortnight to give service users time to adapt, and in case people had appointments which clashed. However, I was concerned that service users would firstly, struggle to retain information between sessions, and secondly, become confused about when sessions were running. I also noted that having conflicting appointments or work would be a consideration for some service users regardless of whether it was weekly or not. It also would mean that I would not be able to offer workshops in other services for a longer period. Thus, we compromised somewhat on timeframe and I shortened the number of learning sessions. I focussed on creating session plans which had specific themes and food content which fit these themes. For example, when discussing moderation, we talked about healthy and unhealthy sources of these, and which ones to have in moderate amounts, rather than the two separately. This was acceptable to the manager on this occasion.

### **Managing dynamics and ambivalent participants**

Some participants were unintentionally disruptive. One, for example, did talk to themselves during the session and did not pay attention to the discussions. This annoyed some other service users. I was somewhat prepared for this, as I assessed challenging behaviour before the workshops started with staff, so was able to plan behaviour management strategies in advance and share these with my co-facilitator before sessions began. During the session I aimed to engage these service users and communicated my expectations calmly and assertively regarding acceptable behaviour. Service users responded well to this and this reduced frequency of criticism towards those being disruptive in sessions. I also praised them for their achievements in sessions and gave 1-1 teaching and cooking training where appropriate, to facilitate their integration into sessions. One service user, over four weeks, became quite pleased that I was delivering sessions, so building trust and rapport was important to their engagement as a form of positive social support.

Some participants in the workshops were ambivalent about participating in healthy eating workshops. They emphasised behaviours which were oppositional to what we were trying to teach, and we dealt with this calmly and with a bit of humour, as they were testing boundaries and ascertaining safety. I acknowledged that taste and enjoyment of food was important but reminded them at times that my job was to promote tasty healthy food as this was the goal of the session. It was important to balance showing understanding with adhering to my objective.

I had discussed this with my workplace contact previously and they suggested using motivational interviewing may be useful for those with milder learning disabilities. This can be useful when trying to address '*sustain*' talk and evoke greater change talk by users with mild learning disabilities who are ambivalent in future interventions (Miller, Rollnick, & Rollnick, 2013) but I did not have much experience or training in this approach. I aim to address this as part of my professional development, particularly in eliciting change talk as this can be difficult, as a future developmental need. This is also where individual interventions can be important, to tailor more effectively to varied needs (Melville et al., 2011).

### **Environmental context**

The most effective way to ensure engagement with health promotion interventions were conducting these in service users' homes. This meant they and people supporting them could be engaged. It also resulted in greater inclusion of those not seen to have a '*weight problem*' as those showing interest became attendees. However, this meant participation in assessment was more variable. The suitability of the learning environment for engaging all users and doing group work also varied significantly as some users were physically obstructed by other clients due to room layout. For those with individual kitchens, we rotated use of these in sessions, but some of these contained more equipment than others, and some service users were more willing to use their kitchen than others. Having a training kitchen with more facilities would have meant more service users could have cooked at the same time rather than preparing or cooking food as individuals doing so one by one, resulting in better time management. Some learners disengaged whilst not participating due to lengthy waiting times for their '*turn*'. This means staff would need to be present to help them as individuals, but they also did not have much active input to give as a result. More financial resources are

needed to be able to use these facilities, and as adults with learning disabilities vary significantly in their processing skills and speed of cooking, this can be potentially quite expensive, unless they are taught individually. However, this may mean they do not experience peer role modelling and are less likely to eat foods they may not otherwise try or express preferences for.

## UNIT 4: TEACHING AND TRAINING

### **Case Study 1: Teaching care workers to support their clients with healthy eating: exploring duty of care and enabling choice**

Adults with mild-moderate learning disabilities generally have unhealthier diets than those in the general population (de Winter et al., 2012; Stancliffe et al., 2011). Most support workers in ██████████ play an important role in assisting clients with learning disabilities to eat healthily, leading planning, shopping and cooking meals for clients. Knowledge of healthy eating guidelines can also be variable amongst this group (Melville et al., 2009; Trip et al., 2016). Additionally, they can perceive conflict between a duty to promote healthy eating and enabling clients to make their own dietary choices, including unhealthy choices (Spanos et al., 2013).

However, Smyth and Bell (2006) explored nuances of choice for adults with learning disabilities. They argued this is influenced by various factors, including familiarity, limited cognitive ability and understanding, and carers' beliefs and attitudes toward healthy eating. Thus, part of the role of trainee health psychologist involved piloting workshops with support workers and managers of services to provide health education and training to address these issues with clients in their services. The session was run on 27th April 2018 with fourteen participants over 3.5 hours. The teaching approach drew on experiential learning theory and communities of practice to help carers to persuade their clients to engage with healthier eating (See Appendix A).

The session began with communicating learning objectives to attendees and setting ground rules collaboratively, including good timekeeping and practice-specific issues such as confidentiality (Carter, 2013). They were also presented with a choice, whether to sample a healthier version of a *'treat'* that had made for the session. This drew on Kolb (1984) by involving experiential learning with staff and giving them opportunity to reflect on whether they decided to accept the offering or not. Previous research suggests empathy is an important affective motivator to encourage health care professionals to reflect on their experience (Vanlaere, Timmermann, Stevens, & Gastmans, 2012). Most had not tried the snack, but little reflective discussion took place, perhaps as this was early in the session. I then collaborated with learners as an entire group to reflect on what they felt *'duty of care'* and *'choice'* meant for service users. This led to discussion of assumptions made by staff

about choices made by clients, involving negotiation of meaning from a joint repertoire to construct new imaginings of what choice could mean for clients (Wenger, 1999) and thus opportunities to introduce healthy eating.

Previous knowledge and experience with clients with learning disabilities was used to create vignettes. These acted as '*exemplars*' for workshop exercises so participants could practise assessing which behaviour strategies would be appropriate to use with individuals as a group. This is partly because social care workers may tend to have a divergent learning style, learning primarily from concrete experience and reflection (Kolb, 1984). The aim was to give them opportunities to actively experiment with application of theoretical strategies and support them to use all four stages of the learning cycle.

It also gave the teacher opportunity to openly reflect on practice and communicate goals and assumptions with participants to facilitate reciprocity and encourage mutual collaboration (Schön, 1988). Learners also discussed strategies with staff from other services. Lave & Wenger (1991) suggested opportunities for newcomers to learn from experienced practitioners on periphery in a safe environment is important to learning in work contexts. This worked well for this task and afterwards learners were instructed to think on how these strategies could be used with their own clients. They shared their experiences of having successfully addressed difficulties in addressing healthier living with individual service users, particularly for example, when collaborating with clients' families was experienced as problematic.

Reflecting in groups early in sessions may be challenging for some participants as this involves vulnerability and openness to new ideas, though it can be an effective means of changing practice (Carter, 2013; Mumford, 1996). Participants were encouraged to share but reassured they had the right not to disclose their reflections if they did not wish to. This was also monitored this when circulating around the room during small group discussions (Carter, 2013). Building good rapport with the group during teaching facilitated this process and some more initially reticent learners became willing to share their experiences, through use of empathy and experience to provide information, guidance and onward referrals where appropriate. Carers supporting a particularly challenging client with disordered eating behaviour also informed the teacher that they were already collaborating with appropriate services to provide effective support, so further referrals were unnecessary.

Overall feedback was very positive and most felt the workshop was relevant to their role (Appendix B). The only criticism received was that a segment on what was considered healthy eating was not delivered during the session. Guidance had been sent on this before the workshop via email but not all attendees would have had good opportunities to check these regularly. Thus, a plan for future sessions would be to briefly educate learners on healthy eating guidelines during the session and give supplementary handouts on this at end of the workshop that they could use in their services future sessions. The session plan was flexible enough to allow this. Ideally there would also be a follow up workshop provided so learners could discuss any problems encountered whilst implementing strategies with clients. However, in practice this would be considered too resource intensive for this organisation.

### **Reflective entry: Not having a co-facilitator for the session**

Prior to this workshop, I recruited a co-facilitator who informed me that they were not available two days before it was piloted. I tried to find an alternative person to help run the session and manage group dynamics, but it was too late to do so. Fortunately, I knew four attendees well in the group and two of them had previously led training workshops within the organisation. The mutual trust and familiarity I had with these learners meant that I could informally ask them for advice to manage the session and they were very encouraging and supportive. Learners were generally very motivated to help clients with healthy eating which also helped me deliver the workshop successfully. The group was also responsive when I managed dynamics and respectful of each other and my trainee status may have also helped as they were considerate of this. In future I would re-confirm attendance of a co-facilitator a few days before to give me time to adjust if they cannot attend.

## References

- Carter, B. (2013). Reflecting in groups. In C. Bulman, & S. Schutz (Eds.), *Reflective practice in nursing* (pp. 93-120). UK: Wiley-Blackwell. Retrieved from <http://0-lib.mylibrary.com.wam.city.ac.uk/ProductDetail.aspx?id=427319>
- de Winter, C. F., Bastiaanse, L. P., Hilgenkamp, T. I. M., Evenhuis, H. M., & Echteld, M. A. (2012). Cardiovascular risk factors (diabetes, hypertension, hypercholesterolemia and metabolic syndrome) in older people with intellectual disability: Results of the HA-ID study, *Research in Developmental Disabilities*, 33(6), 1722-1731.
- Kolb, D. A. (1984). *Experiential learning: Experience as a source of learning and development*. Englewood Cliffs, NJ: Prentice-Hall.
- Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. Cambridge: Cambridge University Press.
- Melville, C. A., Hamilton, S., Miller, S., Boyle, S., Robinson, N., Pert, C., et al. (2009). Carer knowledge and perceptions of healthy lifestyles for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22(3), 298-306. 10.1111/j.1468-3148.2008.00462.x. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2009-05201-008&site=ehost-live>
- Mumford, A. (1996). Effective learners in action learning sets. *Employee Counselling Today*, 8(6), 3-10. 10.1108/13665629610150126. Retrieved from <https://0-doi-org.wam.city.ac.uk/10.1108/13665629610150126>
- Schön, D. A. (1988). *Educating the reflective practitioner: Toward a new design for teaching and learning in the professions*. San Francisco, USA: Jossey-Bass.
- Smyth, C. M., & Bell, D. (2006). From biscuits to boyfriends: The ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*, 34(4), 227-

236. 10.1111/j.1468-3156.2006.00402.x. Retrieved from  
<http://dx.doi.org/10.1111/j.1468-3156.2006.00402.x>

Spanos, D., Hankey, C. R., Boyle, S., Koshy, P., Macmillan, S., Matthews, L., et al. (2013). Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: A qualitative study. *Journal of Intellectual Disability Research*, 57(1), 90-102. 10.1111/j.1365-2788.2011.01530.x

Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Bershadsky, J., Taub, S., et al. (2011). Overweight and obesity among adults with intellectual disabilities who use intellectual disability/developmental disability services in 20 U.S. states. *American Journal on Intellectual and Developmental Disabilities*, 116(6), 401-418. 10.1352/1944-7558-116.6.401. Retrieved from <https://0-doi-org.wam.city.ac.uk/10.1352/1944-7558-116.6.401>

Trip, H., Conder, J., Hale, L., & Whitehead, L. (2016). The role of key workers in supporting people with intellectual disability in the self-management of their diabetes: A qualitative New Zealand study. *Health & Social Care in the Community*, 24(6), 789-798. 10.1111/hsc.12262. Retrieved from <http://dx.doi.org/10.1111/hsc.12262>

Vanlaere, L., Timmermann, M., Stevens, M., & Gastmans, C. (2012). An explorative study of experiences of healthcare providers posing as simulated care receivers in a 'care-ethical' lab. *Nursing Ethics*, 19(1), 68-79. 10.1177/0969733011412103. Retrieved from <http://journals.sagepub.com/doi/full/10.1177/0969733011412103>

Wenger, E. (1999). *Communities of practice: Learning, meaning and identity*. Cambridge: Cambridge University Press.

## Appendix A: Teaching Plan

### Training

Healthy eating for adults with learning disabilities

**Module:** Balancing values in promoting healthy food choices

### Duration:

3.5 hours

**Tutor:** Kiran Bains (Trainee health psychologist)

### Setting

Care staff

**Academic Level 4**

**Date:** April 2018

**No. of students:** 10-15

### Lesson aim:

To effectively support adults with learning disabilities to eat healthily by navigating choice and client resistance

### Specific learning outcomes:

You will be able to:

- Explore perceived dilemmas around duty of care and enabling choice
- Reflect on nuances in decision making around food consumption made by adults with mild-moderate learning disabilities in social care
- Identify opportunities to provide effective emotional and practical social support in line with client needs and preferences
- Consider sources of client resistance

### Links to previous sessions:

This is the first of a two part session. Participants will be expected to have attended training on Mental Capacity Act 2005 (mandatory) before the session. They are also expected to have some understanding of what healthy eating is and access to resources distributed across the organisation before the session.

### Links to future sessions and assessment

This is a standalone session.

Staff members will be formatively assessed on their listening and communication skills (effective positive emotional and practical support) when discussing healthy food choices in scenarios with a client with a learning disability.

### Resources

Healthy food guides from NHS choices (before session)

Handouts with tips on handling challenging behaviour (during session)

Referral guides for supporting clients to access further individual support with healthy eating (end of session)

Handouts with key points from workshop (end of session)

### Evaluation of the session for future use

*Reflect on the planning and organisation of the session, methods and approaches used, content and timing and student participation.*

*The session has been carefully organised but there is somewhat a culture of lateness in the organisation and a key early activity is the taster to facilitate experiential and reflective learning*

*through fostering empathy. If this is missed by a significant number of attendees it may disrupt the session. They may also be careful with their responses in my presence, so I cannot depend on a specific outcome too much (i.e. a lot of them participating in the taster). This audience is also not necessarily the same as a university audience as they may learn better from experience and reflection rather than theory and experimentation. As a result they may forgo new strategies if their experience of implementing these is not supported – i.e. if service users react negatively, so examples and strategies need to be practical in order to facilitate changes in practice and involve them in the process as much as possible. Their understanding of what they have learned will be reflected in their participation in the role play and this is an important opportunity to provide feedback, encouraging positive social support where appropriate. It also involves learning from their ideas of best practice as these may provide useful ‘exemplars’ for future sessions.*

### **Time plan**

<b>Time</b>	<b>Teacher Activity and links to LO</b>	<b>Student Activity</b>	<b>Resources</b>
9.30-10.00	Introduction to session, outlining of session objectives and setting of ground rules  Students will be offered the opportunity to try a healthy snack at the start of the session, teacher will explain benefits to students briefly and informally at the start and ask students to pass around	Students to participate in setting ground rules  Students to decide if they choose to have snack or not and pass these around the group	Flipchart and marker  Healthy snacks
10.00-10.10	Prompt learners to share what they think influenced their choices about whether to have the snack or not	Reflective discussion of why participants chose to try/not try the food offered to them. To be shared with the group	Flip chart and marker
10.10-10.25	Brief talk on healthy eating + benefits. Recap of legal obligations to promote healthy eating to clients and respect choices		
10.25-10.40	Prompt participants to get into groups. Offer students flip chart paper for each small group dealing either with ‘duty of care’ or ‘choice’ to outline what these mean regarding food choices made by clients in usual work contexts. Walk around to facilitate, answer questions and ask task related questions to keep participants focussed as appropriate	Students to contribute what they think of ‘as duty of care’ and ‘choice’, to encourage participation and discussion	Flipchart paper and marker
10.40-	Explore participants		Projector and

10.55	conceptualisations of these ideas, introduce definitions of choice and known influences from literature		PC (if available)
10.55-11.05	Break		
11.05-20	Ask group what they think can influence choices made by their clients (focus on familiarity/habit, availability, understanding, food sensitivities)	Participants to share their ideas about what can influence decision making by their clients	
11.20-11.35	Introduce case studies featuring clients in differing scenarios with barriers to eating healthily (focussed on sources of resistance), and cards with prompts on potential problem-solving strategies. Keep participants in same groups as for second activity if earlier discussions progressed well.	Participants to discuss scenarios within small groups and problem-solving approaches to help these clients engage with healthy eating	Vignettes and prompt cards
11.35-11.55	Group discussion of scenarios and sharing of problem-solving ideas, teacher contributing from practice experience and research where appropriate, record students answers on flipchart	Read out scenarios and ideas they thought would be useful for their own scenario (by a spokesperson for each group).	
11.55-12.15	Set up role plays for staff to practice individual approaches in supporting a client based on key ideas, in groups of 3	Get in groups of 3, then rotate every 5 minutes	
12.15-12.35	Facilitate general discussion about how learners can use this to help their own clients and caveats to consider	Staff to participate in group discussion	
12.35-12.50	Debrief, give handouts and feedback forms	Participants to reflect on session and give feedback	Give handouts for further referrals and on session content

## Appendix B: Feedback Evaluation

Scores (1-5 where one is lowest and 5 highest)										
Participant no.	Appropriate to work setting	Able to ask Questions?	Trainer answered questions meaningfully	Useful info & ideas	Discussion opportunities	Trainer communicated info clearly	Trainer rapport quality	Trainer presented info engagingly	Variety of training methods	Organisational values incorporated into training
1	5	5	5	5	5	5	5	5	5	5
2	5	5	5	5	5	5	5	5	5	5
3	5	5	5	5	5	5	5	5	5	5
4	4	4	4	4	4	4	4	4	4	4
5	4	4	4	4	4	4	4	4	4	4
6	5	5	5	5	5	5	5	5	5	5
7	5	5	5	5	5	5	5	5	5	5
8	5	5	5	5	5	5	5	5	4	5
9	5	5	5	5	5	5	5	5	4	4
10	5	5	5	5	5	5	5	4	3	5
11	5	5	5	5	5	5	5	5	5	5
12	5	5	5	5	5	5	5	5	5	5
13	4	4	4	4	4	4	4	4	4	4
14	4	5	5	5	5	4	4	4	4	4

12 out of 14 learners felt the level of the course was 'about right' (two did not give a rating) whilst all felt the pace was 'about right'. Eleven rated the course 'excellent' whilst the other three rated it 'good'.

### **Areas for Improvement**

Giving some information on healthy eating guidelines and useful sources for further information would be a good beginning. Moreover, generating collaborations with health professionals working within nutrition (i.e. dieticians or appropriately qualified nutritionists) would enable co-delivery of teaching and follow up support so service users could have individually tailored recommendations to improve their diets. This can only be achieved through inter-disciplinary collaboration in future teaching.

## UNIT 4: TEACHING AND TRAINING

### Case Study 2: Teaching adults with learning disabilities about healthy eating

Health education workshops were delivered with adults with mild-moderate learning disabilities accessing the Gate Media Centre in [REDACTED] in November-December 2017. This research suggested many adults with learning disabilities lacked understanding of long-term outcomes of healthy eating. It also suggested education efforts primarily targeted overweight and obese individuals rather than trying to promote healthy living amongst all service users.

Baseline assessments were carried out examining pre-existing knowledge, degree of learning disability and verbal communication skills with eight users interested in attending workshops to tailor materials to audience needs. A measure on challenging behaviour was also administered to assess suitability for group education involvement. Knowledge assessments were based on NICE recommendations for a healthy diet and ascertaining perceived personal relevance of healthy eating principles (See Appendix A for an example of a knowledge assessment). These were adapted to this audience using easy read materials to make these more accessible. Pre-assessments suggested users had some knowledge, particularly that fruit and vegetables were recommended as part of a healthy diet, albeit knowledge of its' benefits were more mixed amongst this group. Several thought only those with a pre-existing condition or weight issues needed to eat healthily and this may reflect a pre-disposition by social care services to target those with a *'problem'*, as had been suggested by the interview study.

The workshops used experiential learning (Kolb, 1984), as this study and another methodologically robust study suggested using *'concrete'* examples to illustrate what healthy eating entailed in practice would be more easily accessible to adults with learning disabilities (McDermott et al., 2012). For example, the first session focussed on tangible benefits of healthy eating that aimed for relevance for learners, involving a small group game linking specific foods to their benefits within the body (See Appendix B for the session plan). This aimed to achieve three things, firstly demonstrate that healthy eating could have health

promoting benefits for all the learners present. Secondly, it aimed to encourage participants to monitor observable and meaningful improvements over time, rather than weight status, which may not be feasible for those with low literacy and numeracy skills. Thirdly it would act as an *'ice breaker'* for learners to foster collaboration and open discussion in future activities involving reflection and discussion of underlying concepts (Kolb, 1984) with support. This is akin to undertaking an *'activation'* task for learners before they take part in the following activities (Ilias & Doikou-Avlidou, 2018). However, it also differed from Ilias & Doikou-Avlidou (2018) as the first task for these teaching sessions aimed to address the lesson's primary objectives. This was because some users may be able to concentrate at the beginning of a session but lose this over time (Bergström et al., 2014).

To aid understanding, the task was simplified by including individual items with several tangible benefits participants could choose from and pictures were also used to aid accessibility (Hollins, Egerton, & Carpenter, 2016; Hollins, Carpenter, Bradley, & Egerton, 2017). The trainee health psychologist leading the session and co-facilitators also aimed to help learners by providing encouragement and guidance where appropriate. Afterwards the group was re-gathered to share answers and discuss these in context of primary learning objectives of the session. The teacher used their own body when appropriate to illustrate meanings such as the relation of food eaten to muscle strength, following Bergström et al. (2014). Learners then tasted some healthy snacks, linked to session themes, for active experimentation to experience healthy eating in practice (Kolb, 1984). This was followed by group discussion of users' health concerns and share ideas of how healthy eating could be encouraged in practice.

The task worked as intended with this group and they interacted well. When the association between task and primary learning objectives was made clear and explicit, they understood this, but users needed support to make this abstract connection. This was due to difficulties in reflecting and associating examples to theory (Kolb, 1984). The task was followed by discussion of users' health concerns and summary of key points of the session. Participants were also given a handout on key points to help aid retention of learning after this and subsequent workshops.

The group discussion was difficult in practice as more learners attended than the eight that originally signalled interest, due to environmental context, as the session was held in a *'drop*

*in*' centre, so people entered and left during this activity, which was disruptive. This consisted of eleven people with two non-service users including one carer. Additionally, some attendees did not display much interest in eating healthily and were engaged in private conversation, rather than wider group discussion. These participants were also challenging perceived importance of health promoting diet, including a volunteer with mild learning disabilities who had initially agreed to facilitate sessions. This is not a unique experience and disruptive behaviour of this nature has been reported by other researchers (Bergström et al., 2014). Subsequently I and other senior co-facilitators decided that it would be appropriate for this individual to attend as a learner rather than facilitator, to minimise risk of confusing other users due to conflicts in modelling behaviour (Bandura, 2001). This helped when teaching workshops in subsequent sessions.

There were four workshops with this group and the attrition rate was high as only five service users participated in the final session. Only three participants conducted baseline and follow up assessments and these did not indicate much change in knowledge. Informal feedback from users of pilot workshops indicated they were enthusiastic about food tasting and motivated to cook novel meals. However formal feedback was not sought as several struggled with assessments, so it was felt this would be very difficult for some to give formally, in a meaningful manner. Thus, this was kept informal and reflective learning was essential to improve session content.

As there was a lag between health education and cooking sessions due to service unavailability, an attempt was made to remind participants of what they had previously learned. This proved to be effortful and time-consuming, thus with later iterations cooking sessions were combined with health education. This facilitated cooking meals with ingredients that had already been visually represented in the session and question participants on their benefits, reminding them where appropriate. In the initial iteration the workshops were 60-90 minutes. However, a cooking and tasting session was integrated into teaching for subsequent iterations at the end of every workshop, so sessions were approximately 120 minutes in length, as didactic teaching was shortened.

Meals chosen aimed to be simple and easy to make. They also aimed to include users with physical impairments that would otherwise inhibit ability to perform manual tasks including chopping ingredients (Bergström et al., 2014). Research also indicated some adults with mild

learning disabilities struggled to understand time so visually accessible colour-coded hourglass timers were used as an aid (McDermott et al., 2012). Additionally, some equipment, including slow cookers, circumvented this and other health and safety concerns expressed by participants such as getting burned when trying to cook meals. Participants engaged well with these and cooking sessions were linked to specific health education workshops.

This workshop and another on less tangible benefits of healthy eating was also delivered in another series of education sessions with another group of adults with mild-moderate learning disabilities living within a care home context. This group consisted of four service users. However, this group, overall, understood the group card sorting task less well and did not engage with this as fully (See Appendix C for the teaching plan and evidence folder for examples of materials used in the session). They struggled to understand associations between foods and individual benefits. It was felt the environment may have hindered this, as it may have helped to have participants move away from the table into smaller groups to aid small group discussion. Encouraging staff involvement in facilitating this would also be helpful. In the next workshop, discussing intangible benefits of healthy eating, the session focussed on how increasing fibre and iron intake could help users in observable ways through picture representations, including how the former could aid digestive health.

The task was also simplified further by using a forced choice paradigm. Learners decided which foods visually grouped together on two separate sheets were better suited to aiding fibre intake. This exercise was repeated with iron intake. As choices were greatly simplified and reduced cognitive load for participants, they were better able to understand and participate in the task (Smyth & Bell, 2006). They were also enthusiastic about cooking as part of the education session and demonstrated greater understanding of which ingredients used aided fibre and iron intake. One ingredient was rich in both so participants were advised they did not need to double their consumption of this to prevent any confusion regarding portion sizes, as over-consumption of some foods and vitamins can cause toxicity.

Another topic was also piloted in a later workshop series and added to the curriculum. This focussed on inclusion of sources of fats and sugar in moderation. In the first iteration both topics were taught separately to avoid cognitive overload and feedback was sought from the workplace contact on teaching performance and how this could be improved (See Appendix

D for the observers' report). They felt the session was well planned, well-structured, learners enjoyed the lesson and were included in tasks but it was unclear if they all understood the content. Additionally, they advised against using abstract concepts such as '*tip of the tongue phenomenon*' or spelling to prompt correct answers to questions due to low literacy levels of adults with learning disabilities. In subsequent sessions I avoided doing the latter and encouraged staff to review handouts given to learners with them to facilitate retention of information as this contained written information. I also made efforts to check understanding of all participants by asking them to discuss with me the key learning points at the end of sessions, though due to cognitive difficulties, some struggled with this. This has been noted as a potential issue in implementing interventions by previous research (Bergström et al., 2014).

### **Reflection: first workshop session**

This session began well. Participants engaged well with the picture sorting task associating specific foods to their benefits in small groups. The group discussion was more fraught with difficulties due to group size and disruption from people entering and leaving, whilst taste testing helped make this manageable. This kept periods of didactic teaching short, containing disruptive behaviour and providing opportunities to assist those with shorter attention span through delivering simplified messages with plenty of repetition. Disruptive behaviour was managed assertively and where appropriate, learners were reminded that the session aimed to educate learners about benefits of healthy eating to help them engage with this. Additionally, a non-service user attended the group discussion and proceeded to share their health concerns with the entire group. These apparently meant this person could not follow a healthy diet. I contained this person's dominance by managing flow of the discussion and managing their input, whilst putting this in their personal context of their health condition. I encouraged others to share their concerns and beliefs and repeated information on benefits of eating healthily that were covered in the first group activity. This was a stressful session to manage, but I focussed on overall learning objectives and this helped with keeping most learners engaged with the session. After this workshop finished, I and my facilitators discussed where changes needed to be made and agreed that we needed to set boundaries on group involvement. We decided to include users interested in learning about healthy eating and their carers only. This helped education delivery for later workshops in this and other settings.

### **Reflection: staff involvement in teaching**

Formative assessments in teaching sessions suggested some participants were able to articulate what they had learned earlier in workshops. However, assessments after the workshop series suggested learning had not been retained by most choosing to maintain attendance and participate in assessments (See Appendix E for overall results and recommendations for future practice). Participants' home environments were used for subsequent health promotion education workshops to facilitate involvement of paid carers in education so they could participate in and reinforce learning outside of sessions. Attendance by staff in sessions varied by context, but this was supplemented by staff workshops where these were taken up. Reinforcement of learning was not assessed after workshops with users. In future I would also assess this with carers and support workers to ascertain whether they reminded participants of what they had learned and whether this was associated with increased knowledge scores of learners.

### **Reflection: Learning modalities**

Bandura (1986) argued individuals learn by observation and by practising activities, particularly the former as cognitive resources are freed from paying attention to motor tasks whilst learning. However, Foti et al. (2017) found learning by observation was easier for those with Williams' Syndrome, but those with Downs' syndrome may struggle with this, whereas they were better able to learn by practising the task. This suggests the underlying cause of learning disability can impact learning by different modalities, not just severity of disability. In most cases I did not know the underlying cause of learning disability, so aimed to incorporate observation and practice in sessions. This was easier to achieve during cooking as this was more practical.

Previous research also suggested pictures are easier for adults with learning disabilities to process without accompanying text (Hollins et al., 2016; Hollins et al., 2017). In practice, it was difficult to adapt handouts to convey key messages from sessions completely by pictures as there was a lack of appropriate resources in picture banks and these can be difficult to create independently. In future I would aim to collaborate with the arts centre more closely to try to co-create these for future workshops. I also learned about resources such as Books Beyond Words, which covers health promotion for adults with learning disabilities and I

would incorporate interactive storytelling to educate learners experientially (Kolb, 1984) on the importance of healthy living.

## References

- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, N.J: Prentice-Hall.
- Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, 52(1), 1-26. 10.1146/annurev.psych.52.1.1
- Bergström, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities-a qualitative study. *Health Education Research*, 29(2), 259-271. 10.1093/her/cyt111
- Foti, F., Menghini, D., Alfieri, P., Costanzo, F., Mandolesi, L., Petrosini, L., & Vicari, S. (2017). Learning by observation and learning by doing in Down and Williams syndromes. *Developmental Science*, 0(0), e12642. 10.1111/desc.12642 Retrieved from <https://doi.org/10.1111/desc.12642>
- Hollins, S., Carpenter, B., Bradley, E., & Egerton, J. (2017). Using wordless books to support clinical consultations. *The Journal of Mental Health Training, Education and Practice*, 12(4), 260-271. 10.1108/JMHTEP-03-2017-0022. Retrieved from <https://doi.org/10.1108/JMHTEP-03-2017-0022>
- Hollins, S., Egerton, J., & Carpenter, B. (2016). Book clubs for people with intellectual disabilities: The evidence and impact on wellbeing and community participation of reading wordless books. *Advances in Mental Health and Intellectual Disabilities*, 10(5), 275-283. 10.1108/AMHID-08-2016-0020. Retrieved from <https://doi.org/10.1108/AMHID-08-2016-0020>
- Ilias, V., & Doikou-Avlidou, M. (2018). Enhancing social interaction of pupils with intellectual disabilities with their general education peers: The outcomes of an intervention programme. *Journal of Research in Special Educational Needs*, 0(0). 10.1111/1471-3802.12410. Retrieved from <https://doi.org/10.1111/1471-3802.12410>
- Kolb, D. A. (1984). *Experiential learning: Experience as a source of learning and development*. Englewood Cliffs, NJ: Prentice-Hall.

McDermott, S., Whitner, W., Thomas-Koger, M., Mann, J. R., Clarkson, J., Barnes, T. L. et al. (2012). An efficacy trial of 'steps to your health', a health promotion programme for adults with intellectual disability. *Health Education Journal*, 71(3), 278-290.  
10.1177/0017896912441240

Smyth, C. M., & Bell, D. (2006). From biscuits to boyfriends: The ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*, 34(4), 227-236. 10.1111/j.1468-3156.2006.00402.x. Retrieved from  
<http://dx.doi.org/10.1111/j.1468-3156.2006.00402.x>

**Appendix A: Knowledge assessment (using easy read)**

**Healthy eating**

**Eating vegetables is good for me.**



**I should eat different types of vegetables.**



**Eating some fruit is good for me.**



**Fruit has sugar in it.**



**Too much sugar is bad for my health.**



**All fat is bad for me.**



**Energy drinks are good for me.**



**If I eat meat it should be:**



Notes: To be filled with attendee as appropriate. Please record any observations (e.g. if they demonstrate understanding of the questions, respond appropriately, are able to communicate). Please also record if they are unsure and unable to decide whether or not they agree with statements given.

## **Appendix B: Session Plan (in correspondence with session co-facilitators)**

Hi both,

So overall structure of the session - it will focus on the positives of eating healthy food.

Overall structure:

1. Introductions (mainly me as they know me as a support worker, not a psychologist in training) and possibly volunteers (depending on how well everyone knows each other)
  
2. Activity - So 5 things that healthy eating can do for a person, involves the group matching pictures of foods to those things (involving pictures and paper plates with the name of the vitamin/mineral/food type on the back)
  - Foods that help you build stronger bones (Calcium)
  - Foods that can help you keep a good mood (fruit and veg)
  - Foods that helps you build stronger muscles (protein)
  - Foods that can be good for your skin (B vitamins)
  - Foods that helps you see in the dark (Vitamin A)
  - Foods that can make you fart (BEANS)
  
3. Then I was thinking a bit of role play, to explain the importance of iron and fibre because these are not so obvious in their benefits, yet very important. Fibre especially, as some evidence suggests that people with learning disabilities can struggle to digest food (though this applies more to those with moderate and severe learning disabilities)
  1. This does involve us pretending to be these things by the way and a bit of acting on our parts. So I was thinking split people into 2 smaller groups where we act it out (ideally, then switch them), but we may need a volunteer to make it work in that case. I was thinking you could be Iron Helena, and I can be blood about to drive you around - I'll ask you what you do, you say I take air around the body so we can use it when we breathe in, then I say what for? To help us make energy, then I take it back when they're done. Then I ask where you come from. You say spinach.
  2. Then Marie, as the voice of wisdom and calm I'd ask you to act as fibre, and me and Helena to act like sugar (but very excited) to get through, it'd be your job to slow us down and relax into our surroundings so the body can deal with us as it's a bit much. Could also involve 1 or 2 service users acting excited with us. Or doing the calming thing with Marie as fibre.
  3. For this we need signs

4. Supplements - being careful with this
5. Then we can talk about healthy eating in general (people having an informal chat, won't try to sort into groups, but have it as part of a break/winding down, with us going around and contributing). We can do a bit of informal tasting at this point.
  
6. Close - I will say at the start I'm not a dietician/nutritionist (but can signpost, generally you can get referrals from GP, or the NHS site is pretty good and we can help them access this for example), but will say that we are here to try and help them eat more healthily (at their own pace), have fun with it and help each other out in a fun way.

I hope that helps. It's not too resource intensive but we'll need:

6 paper plates.

Laminated signs in easy read writing.

Velcro.

Pictures of food (probably more than one copy of some as quite a few answers involve fruit and veg).

Small bits of food like carrot sticks, peppers, hummous, red grapes maybe.

I also am debating about whether to introduce the too much fruit issue at this stage. Don't want people to be suddenly eating loads of that instead of vegetables as it still has a lot of sugar in it. Still open to feedback.

Anyway see you in the next couple of days.

Kind regards

Kiran Bains  
DPsych Health

## Appendix C: Teaching Plan for observed session

### Teaching Plan – session 6

**Training:** Healthy eating for adults with learning disabilities

**Module:** Treats (pt 1)

**Duration:** 2 hours

**Tutor:** Kiran Bains (Trainee health psychologist)

**Co-facilitator:** JP (MSc Health psychology student)

**Setting:** RG

**Learning level:** Mild-moderate learning disability

**Date:** March 22<sup>nd</sup> 2018

**No. of students:** 3-6 students

#### Lesson aim:

To start thinking about eating sugar in moderation and sources of sugar in food

#### Specific learning outcomes:

You will be able to:

- Understand that having too much sugar is not good for our health
- Different sources of sugar in our food (including fruit and snacks such as chocolate and sweets)
- How we can make treats a bit healthier
- The need for moderation

#### Links to previous sessions:

The previous session was about making a healthy pizza, using various vegetables and not too much cheese. We began to teach about moderation.

#### Links to future sessions and assessment

The next session we will have Nutella and strawberries and reiterate the message on moderation. Adults with learning disabilities will be formatively assessed on their understanding of moderation in relation to sugar.

#### Resources

Pictures of sugars, processed food, fruits and chocolates and sweets (groups, few photos but larger size).

Pictures of ingredients for process of making muffins (3-4, simplified).

Portion size guide for fruit and vegetables, to keep.

Handouts with key points from workshop (end of session) – also give to support staff.

#### Evaluation of the session for future use

*Reflect on the planning and organisation of the session, methods and approaches used, content and timing and student participation.*

Participants will quite possibly know that too much sugar is not good for their health, but possibly not understand why this is. We will talk about the impact of sugar on the body, but keep the message simple and ‘concrete’, so participants can visualise this more easily. They probably also know that chocolate and sweets have too much sugar in them but be confused by presence of sugar in fruit as well. To help them understand this a bit better we will go over the role of fibre in fruit slowing sugar down (visually if needed, by straining a pulpy orange through a towel cloth) and suggest that they eat 2 pieces of fruit a day, and 4 or 5 portions of vegetables. We will

explain that vegetables have more water, so less sugar than fruit, and talk about a few examples of what counts as a portion size. We will then make carrot and apple muffins in the kitchen, talk about the sugar in the muffins, and suggest that they have one after dinner as a healthier treat than a chocolate bar. This will improve their knowledge, change their outcome expectancies and help them set a goal for eating more vegetables and fruit. It may also improve their cooking self-efficacy, and providing encouragement, praise and guidance (social support) should also help with this.

### **Time plan**

<b>Time</b>	<b>Teacher Activity and links to LO</b>	<b>Student Activity</b>	<b>Resources</b>
	Preparation of orange and pulpy straining cloth and handouts (by teacher)		
15.15-16.00	Preparation of visual aids for learners and gathering of ingredients for muffin making		
16.00-16.15	Participants arrive. Introduce today's session, welcome everyone. Recap on what we learned about benefits of healthy eating and ask students what they thought of their healthy pizza with vegetables in it	Learners to arrive and settle in.  Learners to be involved in recapping past learning as a group.	
16.15-16.25	Ask learners how many portions of vegetables they think they had last week. Give them approximate answers and give a few examples of what counts as one of their five a day (using pictures if needed)	Participants to discuss with facilitators.	Picture cards from last week showing portion sizes
16.25-16.30	Explain what we plan to do in today's session, and show participants the basic steps visually on making a muffin		Picture cards of muffin making
16.30-16.45	Ask participants about what foods they think has sugar in it and why they think it is not good for them Explain in simple terms that too much sugar can be bad for the body and that it needs time to deal with food appropriately	Participants to share what they believe and sources of sugar they know about	

	(food truck analogy)		
16.45-17.05	Explain that sweets and chocolate do contain sugar, but so does fruit. Explain how fruit works, using the orange and straining cloth to help them visualise it, but explain that having too much fruit can still be bad for your health, and that juice is no more than one of your five a day. Suggest that participants aim for 2 portions of fruit a day, and 5 of vegetables, slowly, over time.	Participants to comment on their observation of what is held back by the straining cloth (i.e. fibre)	
17.05-17.55	Muffin making, including apple sauce if needed (oversee this and show participants the process). Supervise and guide participants through the process, explaining simply how it works	Participants to chop and grate apple and carrots under supervision, mix dry ingredients in one bowl and wet ingredients in another, combine and put ingredients in a baking tray and into the oven	Muffin baking tray, pastry cases, 2 bowls and ingredients
17.55-18.10	Give handouts and put away materials. Debrief on session.		Handouts

## Appendix D: Observers' Report

### London Borough of Hammersmith & Fulham

Learning Disability Service  
Parkview Centre for Health  
and Wellbeing Cranston Court  
56  
Bloemfontein  
Road  
London  
W12 7FG

Tel: 0208 383 6464

Fax: 0208 753 5069

Web: [www.lbhf.gov.uk](http://www.lbhf.gov.uk)



Observation using video film of the cookery planning session (with participants consent).

**Observer: Dr Roman Raczka**

**Student: Kiran Bains**

**Date: 15/06/2018**

### **Overall Comments:**

Overall I found the film to be a really useful illustration of Kiran's work and overall Kiran did a really good piece of work with the group.

In reviewing the film I have highlighted both good practice and also areas of suggested improvement – although please be reassured that these are not meant in any way to be critical (as overall Kiran did a really great job) The following feedback comments are to support Kiran in developing skills.

### **Examples of Good Practice:**

Firstly, examples of good practice as follows:

1. Overall really well planned and structured
2. The group participants appeared to be both engaged and also enjoyed the session
3. The session was well paced to ensure everyone was involved
4. Kiran had clearly given good consideration to the pre-group planning to ensure everything needed was prepared.
5. It was a good idea to use an 'experiment' to illustrate the concept (but as below not sure

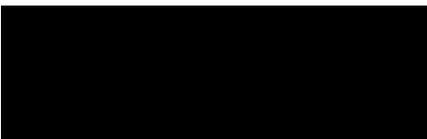
if it was fully understood by all)

6. Kiran worked well to include all participants and maintain eye contact with all.

### Suggestions for improvement:

And secondly, suggestions for improvement – (please note my comments are time based as I watched the films and are therefore not in any order of importance).

1. The participants were seated around the room at the table and on the sofa. It would be much easier to facilitate group discussion and processes if all participants are seated facing each other e.g in a circle.
2. It would also be preferable if Kiran was also seated within the circle as opposed to standing to facilitate this as a collaborative process
3. When prompting people to consider different food you prompt using the suggestion ‘starts with a c’ this is both abstract and dependent on people being able to spell/sound out word and have the ability to generate words in this way – many people with learning disabilities would find this too difficult to do.
4. Kiran used the expression ‘tip of the tongue’ phenomenon – which is also both complex as well as abstract and many people with learning disabilities would find this too difficult to do.
5. When the ‘non group member’ service user entered the room and slammed the door she was told that this was ‘not acceptable’ and appeared to be sent to her room by staff for being rude. Given that this was her own home/kitchen I would question this action. If part of the person’s home is being used for a group activity it is important that the support staff organise alternative activities for other residents who will not be involved in the group to avoid such situations.
6. The printed materials did appear to be very helpful and it was unfortunate that the printer was not working as the use of colour is essential to facilitate good understanding.
7. It was good to use an ‘experiment’ to illustrate the concept but it did not appear to work clearly and so I was not sure if it was fully understood by all.



**Dr Roman Raczka**

**Consultant Lead Clinical  
Psychologist 15/06/18**

## Appendix E: Knowledge assessments

### Scores

Participant	Knowledge		Comments
	Pre	Post	
CA	5	-	T1 Understanding unclear, T2 Insufficient understanding of questions
AB	7	6	
AJ	7	6	
KM	6	1	T2 High levels of reactivity
KO	4	5	
PS	6	6	
PB	-	5	T1 Insufficient understanding of questions

### Recommendations

- Include staff teaching in training workshops for adults with learning disabilities (with a separate additional session or teaching staff how to support service users to increase their knowledge, even if it involves focussing on one or two specific topics according to their needs and goals rather than an extended curriculum.
- Ongoing knowledge assessments with adults with learning disabilities at the end of sessions (one to one) to check they understand content and that this is recorded, as it may aid differentiation between difficulties with initial understanding and retention of information over time.
- Knowledge assessments may need to be re-formulated so they avoid ‘ceiling effects’ with this group. Currently questions are designed for ‘yes/no’ responses to aid understanding, but some learners may just say ‘yes’ in response to all questions rather than actually understand the content. They may need to be a bit more open ended, use pictures rather than words or tactile stimuli to ascertain understanding. This includes putting a picture of sugar under ‘thumbs up’ or ‘thumbs down’ picture. It may also mean separating questions according to valence to make distinctions between ‘good’/’bad’ judgements from ‘correct’/’incorrect’ judgments as this can cause confusion (e.g. sugar may be perceived as ‘bad’ but fruit may be perceived as ‘good’ so putting a question about whether it contains sugar or not may create confusion).
- Alternatively, staff knowledge may need to be tested alongside service user knowledge to assess their understanding. This may be easier to implement in theory, as they may struggle with availability. It may also be important when providing recommendations to services on where they may need to address gaps in service users’ knowledge as staff will be relied upon to fill this gap. This will help effectiveness in sustaining gains in knowledge amongst adults with learning disabilities.

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## SECTION E: SYSTEMATIC REVIEW

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### **Barriers to Equitable Primary health care access experienced by LGBTQ adults for physical general health issues 1997-2018: A Systematic Review**

#### **Abstract**

Background: Previous research suggests LGBTQ adults experience healthcare disparities relative to heterosexuals and cisgender adults. However, the literature has largely focussed on the sexual health, and to an extent, mental health of lesbian and gay individuals (Clarke, Ellis, Peel, & Riggs, 2010). Many individuals access primary care for diagnosis, treatment and management of physical general health issues in Western societies.

Objective: To understand psychological barriers LGBTQ individuals experience relative to heterosexual and cisgender adults in gaining equitable primary care access and the relationship this had to their general health and help-seeking behaviour.

Method: A mixed-methods systematic review was performed, using several health and social science databases, reference lists of included studies and experts in the field and hand-searching key journals for peer-reviewed studies on this topic. Eligible studies focussed on LGBTQ adults seeking primary healthcare for themselves for general rather than mental or sexual health issues. Findings were analysed using the Theoretical Domains Framework (Cane, O'Connor & Michie, 2012).

Results: Six studies were found, reported in seven articles, focussing on experiences of LGBTQ individuals (Adams, McCreanor & Braun, 2008; Adams, McCreanor & Braun,

2013; Björkman & Malterud, 2007; Koh, Zang & Usherwood, 2014; Elliott, Kanouse, Burkhart, Abel, Lyratzopoulos et al., 2015; Edwards & Roekel, 2009; Law, Mathai, Veinot, Webster & Mylopoulos, 2015). Most frequently endorsed barrier domains were skills, social and professional roles and identities, beliefs about capabilities and social influences. Practice implications and further directions for research are discussed.

## **Introduction**

Previous research has found that adults identifying as LGBTQ in Western societies experience greater health disparities than those identifying as heterosexual or cisgender. This is not to neglect the significant diversity and differences in health experienced within different LGBTQ communities, as they differ in terms of race, religion, wealth, age for example (Meyer, 2001). Most research has focussed on sexual health, particularly in gay and bisexual men, which is partly due to longstanding focus about HIV/AIDS in this group, but this has overshadowed others under the LGBTQ umbrella (Clarke et al., 2010). It has also been at the expense of understanding the general physical health problems LGBTQ adults may face and the quality of care and support they receive through the healthcare system. However, as previously noted by Jowett and Peel (2012) and Jowett, Peel and Shaw (2012), sexual health issues can lead to physical health problems and, for example, certain cancers. Conversely, physical health conditions can lead to sexual dysfunction either as direct consequences of illness or through the medication required to treat them.

### **Health disparities experienced by LGBTQ adults relative to the general population**

LGBTQ adults can face considerable social challenges to acceptance and may experience health disparities directly and indirectly due to minority stress. This encompasses lack of self-acceptance, stigma or fear of stigma and experiences of violence and discrimination (Meyer, 2001). A recent large scale survey by Gonzales & Henning-Smith (2017) comparing self-

identified LGB adults to heterosexuals in the US ascertained that sexual minority men were more likely to have ever been told they had cancer or chronic obstructive pulmonary disease (COPD). This may have been at least partly related to them being more likely to be current smokers, yet this was striking as they were also younger than heterosexuals sampled and these illnesses take several years to develop. Lesbians and bisexual women were also more likely to have been diagnosed with COPD or report being current smokers (Gonzales & Henning-Smith, 2017).

In the same study, LGB adults also reported worse overall health than heterosexuals, but lesbians and bisexual women were more likely to report being obese, having arthritis or having recent binge drinking episodes. Bisexual women particularly reported these to a greater degree. This may be because bisexuals tend to experience stigma from both gay and heterosexual communities (Friedman, Dodge, Schick, Herbenick, & Hubach, 2014; Hottes, Gesink, Ferlatte, Brennan, Rhodes et al., 2016). Another UK survey study by Nodin, Peel, Tyler and Rivers (2015) found similar levels of alcohol misuse between sexual minority women and heterosexuals, presumably due to the pub culture which is more prevalent in the UK context, which can encourage alcohol misuse. However, anxieties regarding coming out, presented as a risk factor for alcohol misuse for lesbians and bisexual women. There was no data comparing transgender with cisgender participants on this measure, though transgender youth reported much higher levels of suicide ideation and attempts in this study. Therefore it may be argued that they may also be at higher risk of other health disparities related to lifestyle choices, despite the lack of research with this group.

## **Sexuality and gender minority status does not always mean greater biomedical risk of illness**

As previous researchers have stated it is important that sexual minority status not be conflated with experiencing illness (Jowett & Peel, 2012), and this may also apply to gender minorities. LGBTQ adults also experience the same health conditions as those in the general population and need health care access to manage these appropriately. Experiencing poorer health can lead to greater morbidity and mortality, as with any other segment of the population (DeSalvo, Bloser, Reynolds, He, & Muntner, 2005). These can include those with chronic health conditions, whom can arguably come into contact with a greater number of health professionals as a result of their health issues (Jowett & Peel, 2009). LGBT communities can be a source of support for many (Herek & Garnets, 2007), but they can also be ableist (Jowett & Peel, 2009; Jowett, Peel, & Shaw, 2012). LGBTQ adults can also face cissexism, heterosexism and homophobia when encountering health and social care professionals (Clarke et al., 2010; Hirsch, Ltgen, & Becker, 2016; Jowett & Peel, 2009; Semlyen, Ali, & Flowers, 2017; Vermeir, Jackson, & Marshall, 2018). This is not to say that barriers to equitable healthcare access cannot be overcome (Ussher, 2011), or healthcare professionals are always unsupportive (Jowett & Peel, 2009), but these need to be understood before they can be addressed.

## **The changing landscape of attitudes towards and rights of LGBTQ adults in Western societies in recent years**

A Western context was chosen for this review due to greater homogenisation in sexual and gender identification in the Western world, and structures for provision for health care. Social attitudes toward LGBTQ adults vary between regions within the Western hemisphere. However, there has been a general shift toward cultural acceptance over the last several years

(Stewart & O'Reilly, 2017). For example the rights of LGBTQ adults have changed significantly in recent years in Europe due to human rights directives in this context. This has led to outlaw of discrimination in healthcare settings on the basis of sexuality and gender in member states such as the UK.

### **The primary care context as a point of context**

The most routine point contact with the healthcare system for most adults in Western societies is in primary care settings. Services provided include early screening for illnesses, diagnosis of minor illnesses, prescription of medication, first point of contact for management of long-term conditions and onward referrals for further specialist treatment where appropriate. Although most people may access healthcare through visiting their general practice, there may also be qualitative differences between those who access health treatment through their general practice and those who predominantly use other settings. One of the clearest examples of this is the USA, reliant on a market-based healthcare system. Users of primary care are often insured and have greater affluence than those who access healthcare through using an emergency room. Additionally, users may arguably have greater opportunity to develop a longer lasting relationship with their general practitioner than with most other health professionals. This may be impacted by a variety of factors such as the quality of the doctor-patient interaction (Stablein, Hall, Pervis, & Anthony, 2015). Recent population studies in the USA and Australia by Brown, McNair, Szalacha, Livingston & Hughes (2015), Conron, Mimiaga & Landers (2010) and Solazzo, Gorman & Denney (2017) have found LGB adults are significantly less likely to have a regular general practitioner than their heterosexual counterparts, particularly bisexual women. However, they did not report on the psychological barriers that led to this disparity.

Therefore, the focus of this review is on psychological barriers to equitable primary care access for general health issues faced by LGBTQ adults relative to their heterosexual and cisgender peers.

### **Use of the Theoretical Domains Framework to guide identification of barriers to primary care access in this population**

The Theoretical Domains Framework (Cane, O'Connor, & Michie, 2012) was chosen to synthesise this data as this can guide systematic identification of potential personal, social and environmental barriers to primary health care access in this population. This also offers avenues for structuring evidence based interventions using appropriate behaviour change techniques to address disparities in primary healthcare access for LGBTQ adults (Michie, Atkins, & West, 2014).

## **Method**

### **The review question**

To understand the barriers to equitable healthcare that LGBTQ people face when accessing primary health services in Western societies from 2007 to present.

### **Registration**

The review protocol was registered on PROSPERO under record number CRD42017056048.

### **Inclusion and exclusion criteria**

Original empirical research articles published in peer-reviewed, academic journals in English were included for review. These needed to focus on disparities in primary healthcare access for physical health concerns and involve sexual or gender minority adults identifying under

the LGBTQ umbrella term. Both quantitative and qualitative research articles were eligible for inclusion, but quantitative studies needed to have a heterosexual and/or cisgender group to facilitate comparative analyses. Due to greater homogenisation in sexual or gender identity in Western cultural contexts, only results from Western countries were included in this review. Studies were excluded if they did not focus on barriers to access in primary care (e.g. hospital visits, emergency rooms, secondary or tertiary care such as referrals to specialist treatment services or nursing care, or on if they focussed on overall experience with healthcare professionals). They were also excluded if they did not include at least sexual or gender minority group under the LGBTQ umbrella, if they focussed on mental health or sexual health/HIV status or if they involved participants obtaining care for others (e.g. their children). Studies on adolescents or children, or focussing on special subgroups (e.g. homeless populations, veterans) were also excluded, as were case or intervention studies.

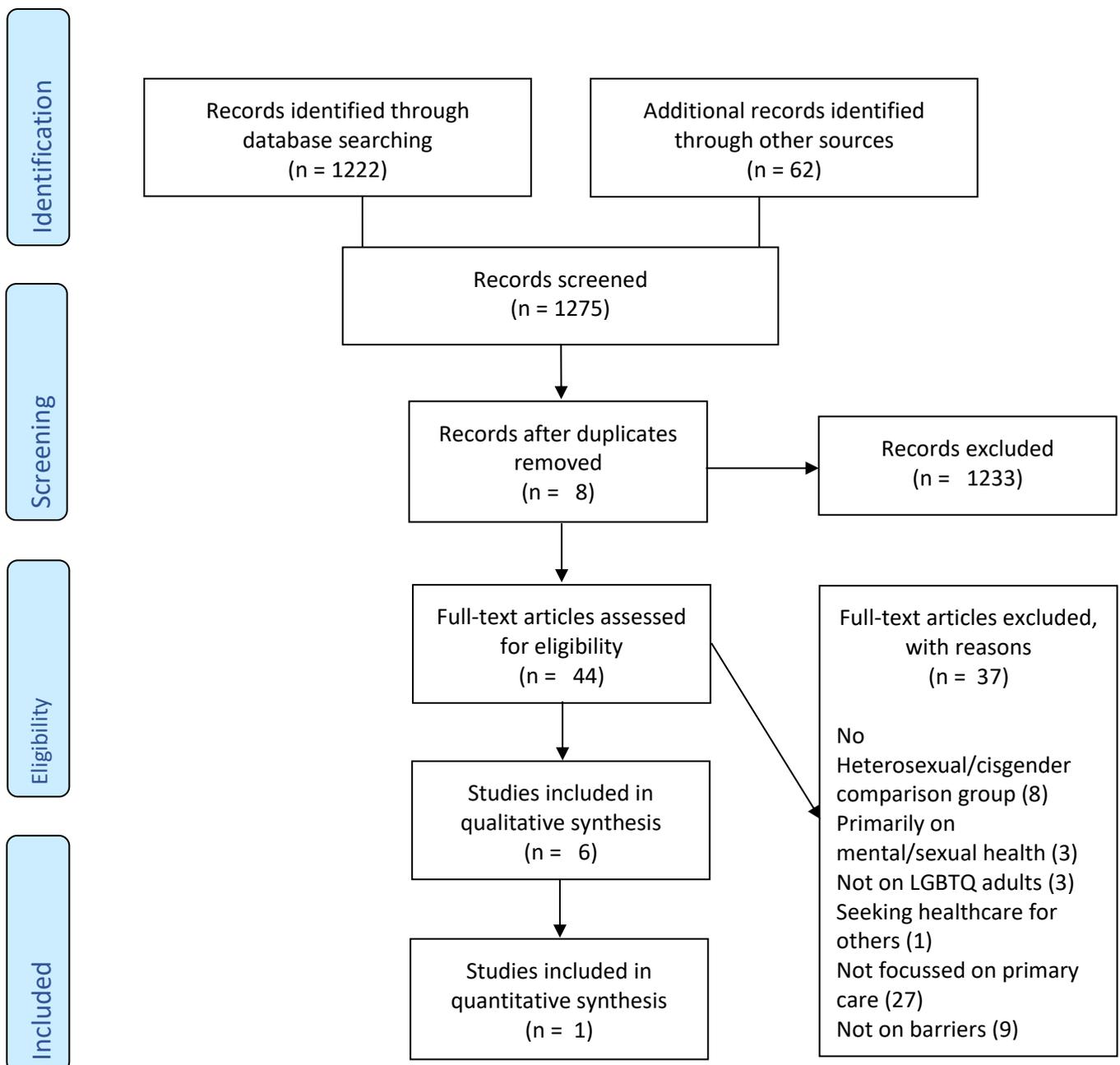
### **Searches and information sources**

The search strategy initially involved searching several health and social science databases: Medline, CINAHL, EMBASE, PsycINFO, SocIndex, Web of Science, IBSS and Social Policy and Practice, Scopus and ScienceDirect. Key word searches were used based on key concepts in the search: Sexual and gender identity, age, physical health, care setting and accessibility, with combined with Boolean operators, use of truncation, phrase and proximity searches as appropriate. This was done in combination with database-specific subject terms searches where appropriate for each database (See Appendix A). This was followed by a hand search of key journals and consulting reference lists of key experts in the field for further studies, looking at the reference list of shortlisted studies and tracking their citations to find further studies for inclusion.

The first reviewer carried out title screening of studies retrieved from the initial search. Once initial shortlisting had been completed, the abstracts and where appropriate, full text, of studies were screened by the first reviewer and a second, independent reviewer for inclusion in the review. Both reviewers then discussed any disagreements until consensus was reached on studies that were eligible for review (See Figure 1). The last search was performed on 15<sup>th</sup> May 2018.



**(Fig 1: PRISMA 2009 Flow Diagram)**



## **Data collection**

Information on participant self-reported sexual/gender identity and other socio-demographic characteristics such as age, ethnicity and socio-economic status was extracted from each study by the author using a standardised data extraction form (see Appendix B). Further information was collected about the country in which research was carried out, and primary outcomes of interest (Table 2). Primary outcomes were self-reported psychological barriers to accessing satisfactory primary care as reported by LGBTQ adults as no studies were found that focussed on perspectives of primary healthcare professionals. Additional outcomes of interest related to association with general health status and help-seeking behaviour. Study authors were contacted where appropriate to gather more data for further analyses if available.

## **Analysis**

Quality analysis was carried out using the Mixed-Methods Analysis Tool (MMAT, Pluye, Robert, Cargo, Bartlett, O’Cathain et al., 2011; Table 2) by the author.

The data was coded and analysed using the Theoretical Domains Framework (Cane et al., 2012) using QSR NVIVO 11 software. The coding schedule is available (Appendix B). Two of the qualitative studies were secondary coded by an independent reviewer. Any discrepancies were resolved through discussion and codes adjusted as appropriate.

Quantitative comparative analyses between LGBTQ adults and heterosexual/cisgender adults were performed using Relative Risk (RR) effect size estimates with inferential tests of statistical significance.

## **Results**

Seven studies were included in this review and these primarily centred on the experiences of LGBQ (lesbian, gay, bisexual, queer) adults; only one had a small subsample of transgender adults and gender minorities (Koh, Kang, & Usherwood, 2014). Studies varied in methodological quality from low to high, though most were of moderate quality (see Table 2).

One study was quantitative (Elliott et al., 2015), a cross-sectional comparative study on adult patient experience of primary healthcare in the UK. They examined the relationship between sexual orientation and trust, communication and satisfaction with primary care professionals (GPs and nurses) and differences in general health status between LGB and heterosexual adults.

The other five were qualitative interview studies with LGB adults about their experiences of primary care. Studies focussed on participants' self-disclosure, help-seeking and management of routine health issues (Adams et al., 2008, 2013; Bjorkman & Malterud, 2007; Edwards & van Roekel, 2009; Koh et al., 2014; Law et al., 2015). Two papers outlined the results of one qualitative research study (Adams et al., 2008; 2013). In both types of studies, participants, particularly those identifying as gay, lesbian or bisexual, tended to be white and well educated. Bisexual participants, particularly women, in quantitative research also tended to be younger than those in other groups. They also tended to be of lower socio-economic status than heterosexual, gay or lesbian participants.

## **Barriers**

The most commonly reported barriers were skills, social and professional roles and identities, beliefs regarding capabilities and social influences (Table 4). It must be noted that LGBTQ participants reported most of the barriers were presented by primary care professionals that

treated them rather than their own behaviour. Some of them, however, were implicit issues in their own decision making.

The most common skills barrier reported by participants related to *'interpersonal skills'* shown by their health care professionals, more frequently reporting aspects of communication from doctors and nurses as *'poor'* or *'very poor'* than heterosexuals (Table 4, Elliot et al., 2015). They also reported a lack of acknowledgment at times when disclosing their sexuality, which led to uncertainty about whether their GP had listened and understood them at times and discomfort and hostility at others (Edwards & van Roekel, 2009; Koh et al., 2014; Law et al., 2015). The latter, along with a lack of trust and rapport, were important reasons why social influences were also a significant barrier according to the TDF framework in all the studies (negative *'social support'*, *'power'* imbalances and *'alienation'* amongst the most commonly used codes for this domain).

Participants generally believed that primary care professionals had a duty not to assume their heterosexuality, by using gender neutral language, though they often did (professional role: social and professional roles and identity). This was consistent across qualitative studies with high to low methodological quality. However, those in Björkman & Malterud (2007) generally believed the onus should be on the LGB person if they felt it was relevant (social role, same domain). However, this study concentrated specifically on the experiences of lesbians accessing primary care, so it is unclear how much this perspectives were shared by other sexual or gender minority adults. In practice most participants in qualitative studies reported managing self-disclosure; only doing so when they felt it was relevant to the issue they consulted for. This meant they had to be experts in their own health needs when visiting their primary care practice, and knowledge was potentially a significant barrier to equitable

healthcare access for general health issues for these participants (code: scientific rationale). Others never disclosed their sexuality, albeit a minority always did so as they felt a doctor should always have their full medical history (Adams et al, 2008; 2013). The variable knowledge of primary care physicians of health disparities that impact LGB adults was raised as a concern by some participants in Adams et al. (2008) and Adams et al. (2013). A lack of education for medical students regarding the health needs of LGBTQ people was also raised by a participant in the study by Koh et al. (2014).

Beliefs about capabilities was a further barrier reported by all studies, as LGB participants were more likely not to have any trust and confidence in their doctors than heterosexuals (Table 5, Elliot et al., 2015). In qualitative studies, LGBTQ participants also seemed to show doubts about the ‘perceived competence’ of some of their doctors. This manifested at times in observations that their GPs may not be well informed about the issues that may particularly impact gay men (Adams et al., 2008; 2013) or concerns about the ability of some GPs to deal with women’s health issues skilfully (Edwards & van Roekel, 2009). Another concern was the substantial effort it could take a transgender adult to find a GP that would be knowledgeable, skilful and willing to deal with the health concerns of transgender individuals (Koh et al., 2014). This also overlaps with lack of availability of appropriate resources under the ‘environmental context & resources’ domain. Participants also frequently worried about hostility and the quality of their care deteriorating if they disclosed their identity and some of their practices, so avoided doing so to prevent this issue in future (‘negative reinforcement’, avoiding punishment: reinforcement domain; outcome expectancies: beliefs about consequences domain). Finally, a few participants expressed concern that GPs would have difficulties in deciding appropriately when sexuality was relevant to diagnosing and treating their health issues by either focussing on it too much, or ignoring it when it mattered,

impacting attention and decision making in the memory, attention and decision-making domain (Adams et al., 2008; Björkman et al., 2007).

Environmental context and resources was a domain frequently raised by participants as presenting barriers, particularly heteronormativity in primary healthcare (i.e. organisational culture). Participants therefore often '*screened*' doctors for acceptance and understanding before deciding whether to stay under their care or self-disclose identity. A lack of time to build trust and rapport in the clinical encounter and avoid assuming heterosexuality was another barrier under this domain (resources). This also overlapped with the Goals domain as participants often wanted to prioritise their quality of care in primary care contexts. This meant they did not disclose their sexual identity unless they saw it as clinically relevant, though they also said it should be a goal when healthcare professionals obtain a medical history for it to be '*comprehensive*' (priority: goals domain, e.g. Edwards and Roekel, 2009). Some also felt that primary care professionals needed to be more motivated to address heterosexism in healthcare contexts (intentions domain). Finally, the qualitative studies suggested this led to negative emotions, including stress, fear and anxiety, for several participants across studies (emotions domain of TDF), which related to avoidance of negative consequences of self-disclosure as discussed earlier.

### **Differences in general health status**

The study by Elliott et al. (2015) suggested there was a relationship between a lack of trust and confidence in doctors and fair/poor rated self-health by participants. Results showed a greater proportion of sexual minorities reported having poor/fair general health status than heterosexuals (Table 6). Bisexuals and those identifying as '*other*' tended to have the greatest relative risk of having '*fair/poor*' self-rated health compared to heterosexuals (RRs 1.324-

1.539) but all effect size estimates were significant ( $p$ s < 0.001) for all sexual minority groups. This study was of high methodological quality with large sample sizes and robust sampling methods to enhance representativeness to the general population, suggesting these may be significant relationships of concern. Nevertheless, these results were interpreted with caution regarding the direction of causality as this study was cross-sectional. Namely, there may have been other factors that explained the relationship between sexuality and poorer self-rated health such as stigma or lifestyle factors which may not have been accounted for in this research study.

Overall, this research does not suggest that all participants had negative experiences with primary care practitioners. Indeed, some had very positive experiences, with physicians that were very accepting and person-centred in their approaches, and they seemed to value this highly, in addition to their technical competence.

## **Discussion**

This systematic review suggests that the most prevalent barriers to equitable access to primary healthcare amongst LGBTQ adults for general health issues arise from difficulties within their relationship with primary care professionals. This particularly holds for the doctor-patient relationship, which may not be surprising as primary care professionals are the first point of contact in the healthcare system for many people in Western countries. General Practitioners are also responsible for diagnosis and management of routine ailments and involved in management of long-term health conditions, so for some people this entails greater familiarity, relationship longevity and need for trust in their doctor (Law et al., 2015). The most frequent barriers to having a strong doctor-patient relationship from the perspectives of LGBTQ adults in the studies were in the Skills, Social and Professional Roles

and Identity, Beliefs about Capabilities and Social Influences domains from the Theoretical Domains Framework (Cane et al., 2012). Participants most commonly reported problems with the way that primary care professionals communicated with them, by using heteronormative language in consultations. This involved showing discomfort or a lack of acknowledgment when participants disclosed their sexuality, or though less common, an outright hostile reaction to self-disclosure. Thus, among the most frequently reported barriers were a lack of interpersonal skill, from the Skills Domain of the Theoretical Domains Framework, and professional boundaries from the Social and Professional Roles and Identity Domain.

It also took time for participants to be able to trust and build rapport with their doctors, if they were able to do so. The cross-sectional study by Elliot et al. (2015) found that whilst there was a small proportion of people in their study that did not have any trust or confidence in their doctors, that lesbian and gay participants were, relative to heterosexual adults, at greatest risk of feeling this way. Those men also identifying as *'other'* and women identifying as bisexual were also at greater risk of not trusting or having confidence in their doctors than heterosexuals. Participants in qualitative studies also perceived that doctors varied significantly in their knowledge of the needs of LGBTQ adults according to their sexuality and gender, such as the physical health disparities they face. Knowledge and beliefs about capabilities, particularly perceived competence of primary care professionals was another key domain barrier in this review.

The qualitative studies also suggested LGB individuals were vulnerable to negative social support from their doctors, power imbalances in the doctor patient relationship and a sense of alienation by the heteronormative culture in the healthcare context. For these reasons the

most frequently endorsed domain in the TDF was social influences on their quality of care. This also meant that barriers in the Environmental Context were issues with organisational culture, acting largely as a stressor and having a negative impact on the care experience of LGBTQ individuals. Heteronormativity and the heterosexual assumption has been widely reported by LGBTQ adults in wider healthcare contexts, so this appears to be a pervasive issue (Jowett & Peel, 2009; Jowett & Peel, 2012; Tjepkema, 2008; Ussher, 2011; Vermeir et al., 2018). Additionally, participants in Law et al. (2015) and Koh et al. (2014) felt that healthcare professionals needed to do more to dismantle heteronormativity in the clinical encounter. Some participants interviewed by Edwards and Roedel (2009) and Koh et al. (2014) also noted that primary care professionals were at times, not motivated to be helpful, so a lack of intention to initiate change was mentioned as a barrier, but moderately so in studies in this review. Nevertheless these barriers may be, in part, why LGB adults are less likely to have a regular General Practitioner than heterosexuals (Conron et al., 2010; McNair, Szalacha, & Hughes, 2011; Solazzo et al., 2017). These studies also found that not having a regular primary care professional was a risk factor in not participating in timely breast and cervical cancer in lesbian and bisexual women, and lack of participation in prostate cancer screening in gay and bisexual men.

The onus was often put on LGBTQ adults in these studies to decide whether or not to disclose their identity to a primary care professional. Whilst a minority reported always doing so and some reported never having self-disclosed their identity, most managed self-disclosure in other ways (Adams et al., 2008; 2013; Koh et al., 2013). Participants frequently reported '*screening*' or interviewing their primary care physicians to assess whether they could self-disclose their identity and certain aspects of their lifestyle before doing so, as part of managing self-disclosure. This involved paying attention to linguistic cues such as gender-

neutral language (e.g. Law et al., 2015), advertising as LGBTQ friendly or presence of relevant literature in waiting rooms, taken as positive cues, or religious symbols, perceived to be negative cues (Koh et al., 2014). They often did this out of concern for the future quality of their relationship with their physicians and the quality of care they would receive (stress, fear and anxiety and avoiding punishment: Emotions and Reinforcement domains).

Participants also regularly took into account gender, sexuality, ethnicity and cultural background of practitioners assessing perceived safety in disclosure. These findings were supported by Semlyen et al. (2017) in their research with British Muslim gay men. Some participants in this study reported reluctance in self-disclosure to practitioners who were from matched cultural and religious backgrounds as they felt that they would be less accepting of their sexuality. The research by Adams and colleagues also suggested a minority of gay men did not necessarily trust gay doctors as they felt they were likely to be part of the same social milieu, and thus may judge some of their personal practices negatively. This suggests that notions of patient-doctor concordance may be more complex than they initially appear as matching on the basis of ethnicity or cultural identity may not be suitable for some LGBTQ adults due to internalised stigma regarding identity or certain practices, including drug and alcohol use.

In Edwards and Roedel (2009) and Koh et al. (2014) participants also reported reaching out to their social networks to find an appropriate primary care practice. However, they noted that for those who were not able or willing to, the consequences could be negative for their wellbeing (outcome expectancies: beliefs about outcomes; resources: Environmental context and resources domain). Others reported having more than one doctor to manage different aspects of their needs (Adams et al., 2008; 2013; Koh et al., 2014). Most only reported self-disclosing their identity when they felt it was relevant in their clinical encounter. This was

potentially problematic as it required participants to be experts in their own health needs before having a consultation (Adams et al., 2008, 2013). This also may mean they would not have timely treatment for their health issues, particularly if these were related to chronic health conditions (Jowett et al., 2012). It could also indicate their own perceived competence was potentially a barrier as well as beliefs about negative outcomes stemming from disclosure and fully trusting physicians with their care. The priority for participants, understandably, was to have the best possible care experience they could, but the steps taken to negotiate stigma could be a barrier as a result in the Goals domain of the TDF.

Some participants in Law et al. (2015) reported fears about how confidential their self-disclosures would be kept if other members of their family were treated by the same primary care practitioner. As electronic records are used more widely in healthcare contexts to share key information and moves are made to ask people about their sexual orientation in healthcare contexts, this concern is likely to become more of an issue. Interestingly, however, Stablein et al. (2015) found that amongst sexual minority men, this was a fear expressed by men who did not trust their healthcare practitioners, and led to avoidance of receiving healthcare in some cases. For those with high levels of trust and rapport, however, confidentiality was not a concern as they trusted healthcare professionals to disclose information on a *'need to know'* basis.

The study by Elliott et al. (2015) also suggested that sexual minorities were at greater risk of reporting *'fair/poor'* general health than heterosexuals, particularly those that identified as bisexual or *'other'*. This was linked to a lack of trust and confidence in doctors, as discussed above. Previous research has linked reporting poor health with greater mortality, so this has

negative implications for the health disparities experienced by LGBTQ people (DeSalvo et al., 2005).

### **Key targets for future interventions and practice**

The findings of this review suggest that the key issue to address to reduce disparities in primary health care provision for sexual minority adults is a heteronormative organisational culture in healthcare contexts. Using Theoretical Domains Framework to guide behaviour change interventions towards this aim (Michie et al., 2014), it would be important to target primary healthcare professionals. They play an important role in making the healthcare environment more inclusive. Firstly, education interventions for primary care physicians about the physical health disparities faced by LGBTQ adults could increase their knowledge, motivation (intentions) and beliefs about capabilities to address these with their sexual and gender minority participants. They could also be informed about the strategies LGBTQ adults may use to manage self-disclosure and use interpersonal skills training to improve their communication skills in consultation. Avoiding making the heterosexual assumption with patients was a recurring recommendation by participants in these studies, for example by using gender-neutral language in consultations, and in other studies (e.g. Hirsch et al., 2016).

Building trust and rapport through acceptance, empathising and listening is another important facet of this, which could be done via role play. In order to reduce issues of heteronormativity in the organisational culture, or primary care environment, flyers to indicate being an LGBTQ friendly practice could be displayed in waiting areas of primary care practices (Hirsch et al., 2016; Koh et al., 2014) and signposting to LGBTQ health and support resources. Information leaflets informing patients about common conditions or illnesses could also include representation of LGBTQ adults where appropriate, or health disparities

faced by this group, though care needs to be taken not to further stigmatise individuals by doing so.

Another potentially important avenue for changing behaviour is to design targeted physical health promotion interventions for LGBTQ adults, accounting for differences in identity and needs. Participants in Adams et al. (2013), for example, appeared to be largely amenable to this, though they felt a sense of *'fatigue'* from the concerted campaigns on improving sexual health, HIV and STI testing that had been a regular feature in the gay community for several years. This reflects the almost exclusive focus on sexual health needs of gay and bisexual men that has dominated the health literature for many years. Nevertheless, this can aid self-disclosure, along with having greater trust and rapport with primary care professionals.

### **Areas for future research**

There was very little involvement of transgender or other gender minority individuals in studies in this review, and future research needs to prioritise exploration of their experiences of primary care for general physical health issues. Although the research base is not well developed, hormonal treatment as part of a wider change in gender identity can have negative health implications, such as liver problems or impaired glucose tolerance (Clarke et al., 2010). Any issues in providing appropriate care to manage these in routine clinical encounters with primary care physicians need to be examined so timely intervention can be made where appropriate. Research also needs to be conducted with primary care practitioners to understand their perspectives on barriers to primary healthcare access for LGBTQ adults for general health problems. Indeed, there needs to be more research on the impact of barriers such as a lack of trust and communication in the doctor patient relationship on other physical

health indicators such as self-reported physical health status, BMI, substance misuse or participation in health screening, including general health checks in the UK context.

### **Strengths and limitations**

There are limitations to this review. Firstly the quantitative study was cross-sectional and more longitudinal research needs to be done to assess impact of lack of trust and communication with primary care physicians and nurses on general health status to establish a causal relationship between the two. Secondly, the review only considered peer reviewed research articles. A more thorough review, including grey literature, may have uncovered more relevant small-scale studies examining psychological barriers to equitable primary care access experienced by LGBTQ adults for general and physical health issues. Thirdly, the studies considered only generally looked at self-reported sexual identity and impact on the clinical encounter. A more thorough measure encompassing attraction and behaviour may impact findings. A previous study by Hottes et al. (2016) found that whilst eighty-six percent of gay men were willing to disclose their sexual identity for a national government health survey, only forty percent of bisexual men were willing to do so. Most stated they would identify as heterosexual. This can distort population estimates of health disparities but is likely due to greater stigma experienced by bisexuals relative to lesbian and gay adults (Friedman et al., 2014).

Nevertheless, this review also contributed to a growing literature examining the healthcare experiences of LGBTQ adults with regard to general physical health issues. As much of the literature has focussed on sexual or mental health of LGBTQ adults (particularly sexual behaviour of men who have sex with men), it seems pertinent to examine relatively unexplored directions for LGBTQ health research. This review also aimed to be thorough, examining both health and social science databases, tracking citations and reference lists,

performing hand searches of key journals in LGBTQ health and primary care journals and examining contributions from key authors in the field. The Theoretical Domains Framework (Cane et al., 2012) was used to analyse findings and generate possible avenues for future intervention, to reduce disparities in physical health and healthcare provision between LGBTQ adults and heterosexual and cisgender adults in the general population.

It is hoped that this will spur on further research on the physical health experiences of LGBTQ adults and novel ways to address one potentially important cause of health disparities that exist between these sub-groups and their heterosexual counterparts, that is heteronormativity in the clinical encounter between primary care practitioners and their LGBTQ patients.

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### **Declaration of conflicts of interest**

None to declare.

## References

- Adams, J., McCreanor, T., & Braun, V. (2008). Doctoring New Zealand's gay men. *The New Zealand Medical Journal*, 121(1287), 11-20. Retrieved from <https://search.proquest.com/openview/89675948fdfad40d427ed85ebb284af0/1?pq-origsite=gscholar&cbl=1056335>
- Adams, J., McCreanor, T., & Braun, V. (2013). Gay men's explanations of health and how to improve it. *Qualitative Health Research*, 23(7), 887-899. 10.1177/1049732313484196
- Bjorkman, M., & Malterud, K. (2007). Being lesbian, does the doctor need to know? *Scandinavian Journal of Primary Health Care*, 25(1), 58-62. 10.1080/02813430601086178
- Brown, R., McNair, R., Szalacha, L., Livingston, P. M., & Hughes, T. (2015). Cancer risk factors, diagnosis and sexual identity in the Australian longitudinal study of women's health. *Women's Health Issues*, 25(5), 509-516. 10.1016/j.whi.2015.04.001
- Cane, J., O'Connor, D., & Michie, S. (2012). Validation of the Theoretical Domains Framework for use in behaviour change and implementation research. *Implementation Science*, 7(1), 37. 10.1186/1748-5908-7-37
- Clarke, V., Ellis, S. J., Peel, E., & Riggs, D., W. (2010). *Lesbian, Gay, Bisexual, Trans and Queer psychology: An introduction*. Cambridge: Cambridge University Press.
- Conron, K. J., Mimiaga, M. J., & Landers, S. J. (2010). A population-based study of sexual orientation identity and gender differences in adult health. *American Journal of Public Health*, 100(10), 1953-60.
- DeSalvo, K. B., Bloser, N., Reynolds, K., He, J., & Muntner, P. (2005). Mortality prediction with a single general self-rated health question: A meta-analysis. *Journal of General Internal Medicine*, 21(3), 267-275. 10.1111/j.1525-1497.2005.00291.x

- Edwards, J., & van Roekel, H. (2009). Gender, sexuality and embodiment: Access to and experience of healthcare by same-sex attracted women in Australia. *Current Sociology*, 57(2), 193-210. 10.1177/0011392108099162
- Elliott, M. N., Kanouse, D. E., Burkhart, Q., Abel, G. A., Lyrtzopoulos, G., Beckett, M. K. et al. (2015). Sexual minorities in England have poorer health and worse health care experiences: A national survey. *Journal of General Internal Medicine*, 30(1), 9-16. 10.1007/s11606-014-2905-y
- Friedman, M. R., Dodge, B., Schick, V., Herbenick, D., & Hubach, R. D. (2014). From bias to bisexual health disparities: Attitudes toward bisexual men and women in the United States. *LGBT Health*, 1(4), 318; 318.
- Gonzales, G., & Henning-Smith, C. (2017). Health disparities by sexual orientation: Results and implications from the behavioral risk factor surveillance system. *Journal of Community Health*, 42(6), 1163-1172. 10.1007/s10900-017-0366-z
- Herek, G. M., & Garnets, L. D. (2007). Sexual orientation and mental health. *Annual Review of Clinical Psychology*, 3, 353-375. 10.1146/annurev.clinpsy.3.022806.091510
- Hirsch, O., Lltgen, K., & Becker, A. (2016). Lesbian womens' access to healthcare, experiences with and expectations towards GPs in German primary care. *BMC Family Practice*, 17(1), 1-9. 10.1186/s12875-016-0562-4
- Hottes, T. S., Gesink, D., Ferlatte, O., Brennan, D. J., Rhodes, A. E., Marchand, R., et al. (2016). Concealment of sexual minority identities in interviewer-administered government surveys and its impact on estimates of suicide ideation among bisexual and gay men. *Journal of Bisexuality*, 16(4), 427-453. 10.1080/15299716.2016.1225622
- Jowett, A., & Peel, E. (2009). Chronic illness in non-heterosexual contexts: An online survey of experiences. *Feminism & Psychology*, 19(4), 454-474. 10.1177/0959353509342770

- Jowett, A., & Peel, E. (2012). Physical health. In Das Nair, R. & Butler, C. (Eds.) *Intersectionality, sexuality and psychological therapies* (pp. 163-184), Chichester, West Sussex, UK: John Wiley & Sons, Ltd.10.1002/9781119967613.ch7
- Jowett, A., Peel, E., & Shaw, R. L. (2012). Sex and diabetes: A thematic analysis of gay and bisexual men's accounts. *Journal of Health Psychology, 17*(3), 409-418. 10.1177/1359105311412838
- Koh, C. S., Kang, M., & Usherwood, T. (2014). 'I demand to be treated as the person I am': Experiences of accessing primary health care for Australian adults who identify as gay, lesbian, bisexual, transgender or queer. *Sexual Health, 11*(3), 258-264. 10.1071/SH14007
- Law, M., Mathai, A., Veinot, P., Webster, F., & Mylopoulos, M. (2015). Exploring lesbian, gay, bisexual, and queer (LGBQ) people's experiences with disclosure of sexual identity to primary care physicians: A qualitative study. *BMC Family Practice, 16*, 175.
- McNair, R., Szalacha, L. A., & Hughes, T. L. (2011). Health status, health service use, and satisfaction according to sexual identity of young Australian women. *Women's Health Issues, 21*(1), 40-47.
- Meyer, I. H. (2001). Why lesbian, gay, bisexual, and transgender public health? *American Journal of Public Health, 91*(6), 859; 859.
- Michie, S., Atkins, L., & West, R. (2014). *The behaviour change wheel: A guide to designing interventions*. Surrey, UK: Silverback Publishing.
- Nodin, N., Peel, E., Tyler, A., & Rivers, I. (2015). *The RaRE research project. LGB&T mental health risk and resilience explored*. Retrieved on 18.05.2018 from: <http://eprints.worc.ac.uk/3743/>
- Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F. et al. (2011). *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews*. Department of Family Medicine, McGill University. Retrieved from <http://mixedmethodsappraisaltoolpublic.pbworks.com>

- Semlyen, J., Ali, A., & Flowers, P. (2017). Intersectional identities and dilemmas in interactions with healthcare professionals: An interpretative phenomenological analysis of British Muslim gay men. *Culture, Health & Sexuality, 19*, 1-13. 10.1080/13691058.2017.1411526. Retrieved from <https://doi.org/10.1080/13691058.2017.1411526>
- Solazzo, A. L., Gorman, B. K., & Denney, J. T. (2017). Cancer screening utilization among U.S. women: How mammogram and pap test use varies among heterosexual, lesbian, and bisexual women. *Population Research and Policy Review, 36*(3), 357-377.
- Stablein, T., Hall, J. L., Pervis, C., & Anthony, D. L. (2015). Negotiating stigma in health care: Disclosure and the role of electronic health records. *Health Sociology Review, 24*(3), 227-241.
- Stewart, K., & O'Reilly, P. (2017). Exploring the attitudes, knowledge and beliefs of nurses and midwives of the healthcare needs of the LGBTQ population: An integrative review. *Nurse Education Today, 53*, 67-77. 10.1016/j.nedt.2017.04.008
- Tjepkema, M. (2008). Health care use among gay, lesbian and bisexual Canadians. *Health Reports, 19*(1), 53-64.
- Ussher, J. M. (2011). Heterocentric practices in health research and health care: Implications for mental health and subjectivity of LGBTQ individuals. *Feminism & Psychology, 19*(4), 567; 567.
- Vermeir, E., Jackson, L. A., & Marshall, E. G. (2018). Barriers to primary and emergency healthcare for Trans adults. *Culture, Health & Sexuality, 20*(2), 232-246. 10.1080/13691058.2017.1338757.

Table 1: Keyword search terms used in databases

Identity	Age	Health	Setting	Equity
Gay	Adult* ( <i>adults</i> )	Physical health	Primary care	Equal*
Homosexual*	“Young adult*”	Illness	Primary health care	Equitab*
Lesbian*			General practice	Disparit*
Two spirit			GP	Inequal*
Bisexual*			Nurse	Access*
Sexual orientation				Barrier*
Sexual minorit*				
Transgender*				
Transsexual*				
Bigender*				
Queer				
Genderqueer				
“Gender dysphoria”				
“Gender identity disorder”				
LGB*				

Table 2: Participant characteristics in studies

Authors (Year) Country (city/US State)	Sample (n)	Sexual/gender identity (n)	Age (yrs)	Gender	SES (most freq)	Race/ethnicity
<b>Elliott, Kanouse, Burkhart, Abel, Lyratzopoulos et al. (2015)</b> UK (national)	2,115,335	1,785,832 heterosexuals 12,346 gay men 6,324 lesbians 8827 bisexuals 14,268 other 287,738 prefer not to say/missing	H: 35-44 G: 35-44 L: 35-44 B: 25-34 O: 35-44 P/M: 35-44	57.6% women 42.4% men	H: Least deprived G: Most deprived L: Most deprived B: Most deprived O: Most deprived P/M: Most deprived	86.1% white 2.7% black 11.2% other
<b>Adams, McCreanor &amp; Braun (2008), (2013)</b> New Zealand (Auckland)	45	45 gay men	37	Men	Middle	55.6% white 13.3% Asian/Indian 31.1% other
<b>Bjorkman &amp; Malterud (2007)</b> Norway (Oslo)	6	6 lesbians	41	Women	NR	NR
<b>Edwards &amp; van Roekel (2009)</b> Australia (rural)	10	10 LBQ women	50s	Women	Middle	9 white 1 Aboriginal
<b>Law, Mathai, Veinot, Webster &amp; Mylopoulos (2015)</b>	12	12 LGBTQ sexual minority adults	32.5	6 men, 6 women	Middle	NR

Canada (Toronto)						
<b>Koh, Zang &amp; Usherwood</b>	99	49 gay men	20-29	NR	NR	NR
<b>(2014)</b>		35 lesbians				
<b>Australia (various)</b>		13 bisexuals				
		3 transgender adults				
		8 queer adults				
		6 other				

Table 3: Quality analysis using MMAT. \*Quantitative – control for confounding factors and appropriate model, qualitative – relevance of analytical approach to answering question

Authors	Study Design	Clear research objective	Appropriate method to address objective	Sampling strategy (1-4)	Response rate (1-4)	Measures (1-3)	Analysis (1-3)*	Relating findings to context (1-4)	Acknowledg e researcher influence (1-4)	Overall quality rating
<b>Elliott, Kanouse, Burkhart, Abel, Lyratzopoulos, et al. (2015)</b>	Cross-sectional survey	√	√	4	2.5	2	3	N/A	N/A	High
<b>Adams, McCreanor &amp; Braun (2008), (2013)</b>	Qualitative focus group interviews	√	√	4	NR	N/A	3	4	4	High
<b>Bjorkman &amp; Malterud</b>	Qualitative interviews	√	√	3	NR	N/A	3	3	1	Moderate-High

<b>(2007)</b>										
<b>Edwards &amp; van Roekel (2009)</b>	Qualitative interviews	√	√	4	NR	N/A	3	4	0	Moderate
<b>Koh, Zang &amp; Underwood (2014)</b>	Qualitative online survey	√	√	4	NR	3	3	3	0	Moderate-High
<b>Law, Mathai, Veinot, Webster &amp; Mylopoulos (2015)</b>	Qualitative interviews	√	√	2	NR	N/A	3	2	0	Low-Moderate

Table 4: Barriers to equitable healthcare access by TDF Domains

<b>TDF Domain (example code)</b>	<b>Study(ies) reported in (0-6)</b>	<b>Example (study)</b>
<b>Knowledge (Scientific rationale)</b>	5	“I know that my doctor is not altogether up to date with things that might affect gay men more than they might affect straight men and their families, and so that’s why I go to a different doctor for gay stuff.” (Adams et al., 2008; Adams et al., 2013)
<b>Skills (Interpersonal skills)</b>	6	“If somebody asks me if I have a boyfriend, it puts my back up but if somebody asks if I have a partner, that’s a different story and that’s a good indicator that somebody, you know, doesn’t necessarily assume that, you know, my partner is a boy.” (Law et al., 2015)
<b>Social/professional role &amp; identity (Social and professional identity)</b>	6	“A transgendered friend of mine had to search through multiple GPs before finding one that would treat her. It ended up being a Chinese doctor. An Indian male, Indian female were unwilling to treat her due to religion.” (Koh et al., 2014)
<b>Beliefs about Capabilities (Perceived competence)</b>	6	Moderator (M): “Why is it essential for you to have a gay doctor?” P: “I guess so that one can talk openly about, I guess, one’s practices and one’s attitudes to someone who knows where you’re coming from.” (Adams et al., 2008; Adams et al., 2013)
<b>Optimism</b>	NR	
<b>Beliefs about Consequences</b>	5	“I do not wish to tell them for fear of a change in how I am treated.” (Koh et al., 2014)

<b>(Outcome expectancies)</b>		
<b>Reinforcement (negative reinforcement)</b>	5	‘You do have to expose who and what you are and it is never easy. You know regardless of the fact that at the end of the day we are all a lot more enlightened and we can tell people to go to hell, you really don’t ever want to expose yourself to people’s nastiness I guess.’ (Edwards & van Roekel, 2009)
<b>Intentions (motivation/Stages of Change)</b>	2	“Probably being in the profession [Colleen is a nurse], I am actually pretty hard on them because I see a lot of not very helpful or not really that interested” (Edwards & van Roekel, 2009)
<b>Goals (goal priority)</b>	5	My GP doesn’t know that I am gay. Well, he might, but I haven’t told him. I don’t know, but, I mean, it might be important, but it’s, I have never had an issue that I needed to bring up that made it necessary, and it is one of those things you tell on a need-to-know basis, really. (Adams et al., 2008; 2013)
<b>Memory, Attention and Decision Processes (attention, decision-making)</b>	5	“Or prejudices or that it will be difficult for the doctor so that I don’t get good treatment, because he is so preoccupied with me being a lesbian, and that he then erects a barrier against me or something.” (Bjorkman & Malterud, 2007)
<b>Environmental Context and Resources (Resources)</b>	5	“I already think that doctors [...] they don’t have a lot of time, they just have like 10 minutes for you [...] They make a whole lot of assumptions because they don’t have the time.” (Law et al., 2015)

<b>Social Influences (Negative social support)</b>	6	“[The GP] continually spoke to me as if I were heterosexual...even after I told them I was a lesbian.” (Koh et al., 2014)
<b>Behavioural regulation</b>	NR	
<b>Emotions (negative affect)</b>	5	“Well, you know how many times do you have to keep coming up to somebody, you know, if I looked the part, if I dressed like butch-lesbian or something like that, then it would be different I think I just get frustrated, this question I’ve asked myself many times, how many times do you have to come out?” (Law et al., 2015)

Table 5: Differences in relative risk for poor trust and communication between LGB adults and heterosexuals

	Relative Risk s95% CIs)				
	Heterosexual (ref)	Gay men/Lesbians	Bisexuals	Other	Prefer not to say/missing
<b>Men</b>					
No trust and confidence in doctor	3.6%	5.55% 1.555 (1.308-1.770) p < 0.001	4.25% 1.195 (0.064-1.464) p < = 0.06	5.0% 1.387 (1.244-1.548) p < 0.001	3.9% 1.083 (1.05-1.118) p < 0.0002
Doctor communication Any item=poor/very poor	9.0%	13.5% 1.500 (1.366-2.748) p < 0.001	12.5% 1.389 (1.135-1.630) p < 0.001	10.35% 1.15 (0.941-1.351) p = 0.007	9.05% 1 (0.955-1.054) p = 0.93
Nurse communication Any item=poor/very poor	4.2%	7.0% 1.666 (1.420-1.947) p < 0.001	7.35% 1.740 (1.256-2.263) p < 0.001	6.7% 1.595 (1.256-1.961) p < 0.001	5.25% 1.238 (1.153-1.376) p < 0.001
<b>Women</b>					
No trust and confidence in doctor	3.85%	5.25% 1.358 (1.159-1.662) p < 0.001	5.3% 1.357 (1.034-1.709) p < 0.001	4.3% 1.101 (0.871-1.358) p = 0.17	4.05% 1.026 (0.952-1.099) p = 0.20
Doctor communication Any item=poor/very poor	9.3%	11.65% 1.258 (1.092-1.408) p < 0.001	12.8% 1.376 (1.208-1.539) p < 0.001	9.2% 0.989 (0.853-1.121) p = 0.83	9.15% 0.978 (0.936-1.032) p = 0.23
Nurse communication Any item=poor/very poor	4.55%	7.75% 1.732 (1.442-1.959) p < 0.001	6.7% 1.491 (1.146-1.79) p < 0.001	5.25% 1.177 (0.866-1.477) p = 0.02	5.1% 1.133 (1.039-1.203) p < 0.001

Table 6: Differences in relative risk for poor/fair general health status between LGB adults and heterosexuals

		Relative Risk (95% CIs)				
Men		Heterosexual (ref)	Gay men/Lesbians	Bisexuals	Other	Prefer not to say/missing
Fair/poor general health	(%) RR CIs	19.6	21.85 1.115 (1.077-1.262) p < 0.001	26.35 1.344 (1.285-1.402) p < 0.001	26.8 1.367 (1.307-1.426) p < 0.001	24.35% 1.083 (1.05-1.118) p < 0.001
Women						
Fair/poor general health	(%) RR CIs	20.5	24.9 1.215 (1.166-1.262) p < 0.001	31.55 1.539 (1.486-1.596) p < 0.001	27.15 1.324 (1.283-1.365) p < 0.001	24.75 1.207 (1.198-1.216) p < 0.001

## Appendix A: Searches of different databases

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#	Searches	Results	Type	Actions	Annotations
1	homosexuality/ or psychosexual disorders/ or gender identity/	198	Advanced	Display Results More	Contract
2	(gay* or lesbian* or bisexual* or homosexual* or "two spirit" or "sexual orientation" or "sexual minority" or LGB* or transgender* or transsexual* or bigender or queer or genderqueer or "gender dysphoria" or "gender identity disorder").mp. [mp=abstract, heading words, title]	256	Advanced	Display Results More	
3	1 or 2	349	Advanced	Display Results More	
4	exp adult/	25677	Advanced	Display Results More	
5	(adult* or (young and adult)).mp. [mp=abstract, heading words, title]	22012	Advanced	Display Results More	
6	4 or 5	33160	Advanced	Display Results More	
7	Health/ or exp Health status/ or diseases/ or exp disease/	13010	Advanced	Display Results More	
8	(physical and (health or ill)).mp. [mp=abstract, heading words, title]	9706	Advanced	Display Results More	
9	7 or 8	21209	Advanced	Display Results More	
10	Family practice/ or Primary health care/ or Physicians/	2252	Advanced	Display Results More	
11	(primary N10* care or primary health care or general pract* or GP or nurse*).mp. [mp=abstract, heading words, title]	7782	Advanced	Display Results More	
12	10 or 11	8814	Advanced	Display Results More	
13	exp health services accessibility/	1022	Advanced	Display Results More	
14	(equal* or equit* or disparit* or inequal* or barrier* or access*).mp. [mp=abstract, heading words, title]	10906	Advanced	Display Results More	
15	13 or 14	10906	Advanced	Display Results More	
16	3 and 6 and 9 and 12 and 15	0	Advanced	Save More	

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1	(gay* or lesbian* or bisexual* or homosexual* or "two spirit" or "sexual orientation" or "sexual minority" or LGB* or transgender* or transsexual* or bigender or queer or genderqueer or "gender dysphoria" or "gender identity disorder").mp. [mp=abstract, title, publication type, heading word, accession number]	4016	Advanced	Display Results More	Contract
2	(physical and (health or ill)).mp. [mp=abstract, title, publication type, heading word, accession number]	12776	Advanced	Display Results More	
3	(adult* or (young and adult)).mp. [mp=abstract, title, publication type, heading word, accession number]	39506	Advanced	Display Results More	
4	(primary N10* care or primary health care or general pract* or GP or nurse*).mp. [mp=abstract, title, publication type, heading word, accession number]	14891	Advanced	Display Results More	
5	(equal* or equit* or disparit* or inequal* or barrier* or access*).mp. [mp=abstract, title, publication type, heading word, accession number]	52458	Advanced	Display Results More	
6	1 and 2 and 3 and 4 and 5	0	Advanced	Save More	

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1	exp Sexual orientation groups/ or exp homosexual men/ or exp Lesbians/ or exp homosexuals/ or exp Bisexual men/ or exp Homosexuality/ or exp sexual orientation/ or exp transgendered people/ or exp Bisexuals/ or exp transsexualism/ or exp gender dysphoria/	952	Advanced	Display Results More ▾	Contract
2	(gay* or lesbian* or bisexual* or homosexual* or "two spirit" or "sexual orientation" or "sexual minority" or LGB* or transgender* or transsexual* or bigender or queer or genderqueer or "gender dysphoria" or "gender identity disorder").mp. [mp=title, other title, abstract, heading words]	1280	Advanced	Display Results More ▾	
3	1 or 2	1298	Advanced	Display Results More ▾	
4	exp Young adults/ or exp Adults/	21060	Advanced	Display Results More ▾	
5	(adult* or (young and adult)).mp. [mp=title, other title, abstract, heading words]	14722	Advanced	Display Results More ▾	
6	4 or 5	31213	Advanced	Display Results More ▾	
7	exp health/ or exp diseases/ or exp ill health/	70021	Advanced	Display Results More ▾	
8	(physical and (health or ill)).mp. [mp=title, other title, abstract, heading words]	7594	Advanced	Display Results More ▾	
9	7 or 8	74489	Advanced	Display Results More ▾	
10	exp primary care/ or exp general practice/ or exp family health services/ or primary care nurses/ or primary health workers/ or primary care nursing/ or exp General practitioners/	30146	Advanced	Display Results More ▾	
11	(primary N10* care or primary health care or general pract* or GP or nurse*).mp. [mp=title, other title, abstract, heading words]	59114	Advanced	Display Results More ▾	
12	10 or 11	66823	Advanced	Display Results More ▾	
13	exp equality/ or exp sexual orientation equality/ or exp equity/ or exp health inequalities/ or exp access to health services/ or exp Health needs/	14440	Advanced	Display Results More ▾	
14	(equal* or equit* or disparit* or inequal* or barrier* or access*).mp. [mp=title, other title, abstract, heading words]	41413	Advanced	Display Results More ▾	
15	13 or 14	42944	Advanced	Display Results More ▾	
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#	Searches	Results	Type	Actions	Annotations
1	exp homosexual female/ or exp homosexual male/ or exp homosexuality/ or exp lgbt people/ or sexual orientation/ or exp bisexuality/ or exp gender identity/ or sexual minority/ or exp lesbian/ or exp male to female transgender/ or exp female to male transgender/ or exp transgender/ or exp transsexualism/ or exp gender dysphoria/ or transsexuality.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	46348	Advanced	Display Results More ▾	Contract
2	(gay* or lesbian* or bisexual* or homosexual* or "two spirit" or "sexual orientation" or "sexual minority" or LGB* or transgender* or transsexual* or bigender or queer or genderqueer or "gender dysphoria" or "gender identity disorder").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	50155	Advanced	Display Results More ▾	
3	1 or 2	60575	Advanced	Display Results More ▾	
4	exp adulthood/ or exp young adult/ or adult/	5933296	Advanced	Display Results More ▾	
5	(adult* or (young and adult)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	6515743	Advanced	Display Results More ▾	
6	4 or 5	6577289	Advanced	Display Results More ▾	
7	health/ or physical disease/	223115	Advanced	Display Results More ▾	
8	(physical and (health or ill)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	294782	Advanced	Display Results More ▾	
9	7 or 8	484599	Advanced	Display Results More ▾	
10	exp primary medical care/ or exp primary health care/ or exp general practice/ or exp general practitioner/ or exp nurse practitioner/	294346	Advanced	Display Results More ▾	
11	(primary N10* care or primary health care or general pract* or GP or nurse*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	640248	Advanced	Display Results More ▾	
12	10 or 11	699460	Advanced	Display Results More ▾	
13	exp health disparity/ or exp health care access/ or exp health equity/	65321	Advanced	Display Results More ▾	
14	(equal* or equit* or disparit* or inequal* or barrier* or access*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	1294155	Advanced	Display Results More ▾	
15	13 or 14	1294155	Advanced	Display Results More ▾	
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#	Searches	Results	Type	Actions	Annotations
1	exp homosexuality/ or exp bisexuality/ or lesbianism/ or homosexual women/ or homosexuality/ or exp homosexual men/ or exp homosexual transmission/ or exp homosexual women/ or exp men who have sex with men/	10323	Advanced	Display Results More ▾	Contract
2	(gay* or lesbian* or bisexual* or homosexual* or "two spirit" or "sexual orientation" or "sexual minority" or LGBT* or transgender* or transsexual* or bigender or queer or genderqueer or "gender dysphoria" or "gender identity disorder").mp. [mp=abstract, title, original title, broad terms, heading words, identifiers, cabicodes]	13374	Advanced	Display Results More ▾	
3	1 or 2	14131	Advanced	Display Results More ▾	
4	exp health/ or diseases/ or exp illness/	214794	Advanced	Display Results More ▾	
5	(physical and (health or ill)).mp. [mp=abstract, title, original title, broad terms, heading words, identifiers, cabicodes]	50580	Advanced	Display Results More ▾	
6	4 or 5	246296	Advanced	Display Results More ▾	
7	exp middle-aged adults/ or exp adults/ or exp young adults/	69167	Advanced	Display Results More ▾	
8	(adult* or (young and adult)).mp. [mp=abstract, title, original title, broad terms, heading words, identifiers, cabicodes]	249993	Advanced	Display Results More ▾	
9	7 or 8	249993	Advanced	Display Results More ▾	
10	exp primary health care/ or exp general practitioners/	12310	Advanced	Display Results More ▾	
11	(primary N10' care or primary health care or general pract* or GP or nurse*).mp. [mp=abstract, title, original title, broad terms, heading words, identifiers, cabicodes]	43588	Advanced	Display Results More ▾	
12	10 or 11	43588	Advanced	Display Results More ▾	
13	exp health inequalities/ or exp barriers/ or "right of access"/ or access/	10815	Advanced	Display Results More ▾	
14	(equal* or equit* or disparit* or inequal* or barrier* or access*).mp. [mp=abstract, title, original title, broad terms, heading words, identifiers, cabicodes]	155116	Advanced	Display Results More ▾	
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Did you mean (MAINSUBJECT.EXACT("Homosexuality") OR MAINSUBJECT.EXACT("Sexual orientation") OR MAINSUBJECT.EXACT("Bisexuality") OR MAINSUBJECT.EXACT("Homophobia") OR MAINSUBJECT.EXACT("Gays & lesbians") OR MAINSUBJECT.EXACT("Gender identity") OR MAINSUBJECT.EXACT("Transgender persons") OR MAINSUBJECT.EXACT("transferrability") OR gay\* OR lesbian\* OR bisexual\* OR homosexual\* OR "two spirit" OR "sexual orientation" OR "sexual minority" OR LGBT\* OR transgender\* OR transsexual\* OR biggender OR queer OR bendomeer OR "gender dysphoria" OR "gender identity disorder") AND (MAINSUBJECT.EXACT("Young adults") OR MAINSUBJECT.EXACT("Adults") OR adult OR (young AND adult\*)) AND (MAINSUBJECT.EXACT("Disease") OR MAINSUBJECT.EXACT("Illnesses") OR MAINSUBJECT.EXACT("Health") OR (physical AND (health OR ill))) AND (MAINSUBJECT.EXACT("Primary care") OR MAINSUBJECT.EXACT("Family physicians") OR MAINSUBJECT.EXACT("Practice nursing") OR (primary\*care) OR "general practi\*" OR GP OR nurse) AND (MAINSUBJECT.EXACT("Health disparities") OR MAINSUBJECT.EXACT("Equality") OR MAINSUBJECT.EXACT("Health care access") OR MAINSUBJECT.EXACT("Inequality") OR equal\* OR equit\* OR disparit\* OR inequal\* OR barrier\* OR access\*)

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 Everett, Bethany G, Mollborn, Stefanie. *Population Research and Policy Review*, Dordrecht Vol. 33, Iss. 4, (Aug 2014). 553-577.  
 ...by the lack of **lesbian, gay, bisexual, and transgender (LGBT)** sensitive training  
 ...sexual orientation identity during **young adulthood**. We use binary logistic  
 ...**bisexual, and gay**) to determine if the effect of gender varies by **sexual**

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S6	AB equal* OR equit* OR disparit* OR inequal* OR barrier* OR access* OR (DE "HEALTH disparities") AND (DE "EQUALITY" OR DE "EQUAL rights" OR DE "EQUITY" OR DE "FAIRNESS" OR DE "PARITY (Social sciences)")	Search modes - Boolean/Phrase	<a href="#">View Results (1,351,035)</a> <a href="#">View Details</a> <a href="#">Edit</a>
S5	AB (primary N/10 care) OR "primary health care" OR "general practi*" OR GP OR nurse OR (DE "PRIMARY care (Medicine)" OR DE "MEDICAL care") OR (DE "FAMILY medicine" OR DE "FAMILY nursing" OR DE "PHYSICIANS (General practice)")	Search modes - Boolean/Phrase	<a href="#">View Results (464,793)</a> <a href="#">View Details</a> <a href="#">Edit</a>
S4	AB physical AND (health* OR ill*) OR DE "HEALTH" OR DE "WELL-being" OR DE "SICK" OR DE "DISEASES" OR DE "PATHOLOGY"	Search modes - Boolean/Phrase	<a href="#">View Results (415,676)</a> <a href="#">View Details</a> <a href="#">Edit</a>
S3	AB adult* OR "young adult" OR DE "ADULTS" OR DE "YOUNG adults"	Search modes - Boolean/Phrase	<a href="#">View Results (596,065)</a> <a href="#">View Details</a> <a href="#">Edit</a>
S2	((((DE "LGBT people" OR DE "SEXUAL minorities" OR DE "BISEXUALS" OR DE "GAY people" OR DE "LESBIANS" OR DE "SEXUAL orientation") OR (DE "HOMOSEXUALITY" OR DE "GENDER identity" OR DE "TRANSEXUALISM") OR (DE "GAY men") OR (DE "TRANSGENDER people" OR DE "TWO-spirit people" OR DE "GENDER-variant people" OR DE "TRANSGENDERISM") OR (DE "TRANSEXUALS") OR (DE "GENDER dysphoria")	Search modes - Boolean/Phrase	<a href="#">View Results (38,691)</a> <a href="#">View Details</a> <a href="#">Edit</a>
S1	AB gay OR lesbian* OR bisexual* OR homosexual* OR (two spirit) OR (sexual N/5 orientation) OR (sexual n/5 minorit*) OR LGB* OR transgender* OR transsexual* OR bigender OR queer OR genderqueer OR "gender dysphoria" OR "gender identity disorder"	Search modes - Boolean/Phrase	<a href="#">View Results (90,211)</a> <a href="#">View Details</a> <a href="#">Edit</a>

Refine Results Search Results: 1 - 7 of 7

Current Search 1. Mental health, sexual identity, and interpersonal violence: Findings from the Australian Longitudinal Women's health study

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Select / deselect all | Search with AND | Search with OR | Delete Searches | Refresh Search Results

Search ID#	Search Terms	Search Options	Actions
S8	S2 AND S3 AND S4 AND S5 AND S7	Search modes - Boolean/Phrase	View Results (24)   View Details   Edit
S7	S1 OR S6	Search modes - Boolean/Phrase	View Results (21,147)   View Details   Edit
S6	MH "GLBT Persons" OR (MH "Gay Persons") OR (MH "Gay Men") OR (MH "Bisexuals") OR (MH "Transgender Persons") OR (MH "Lesbians") OR (MH "Transsexuals") OR (MH "Homophobia") OR (MH "Heterosexuality") OR (MH "Gender Dysphoria") OR (MH "Transsexualism") OR (MH "Sexual and Gender Disorders") OR (MH "Gender Identity")	Search modes - Boolean/Phrase	View Results (18,475)   View Details   Edit
S5	AB equal* OR equit* OR disparit* OR inequal* OR barrier* OR access* OR (MH "Healthcare Disparities") OR (MH "Health Services Accessibility")	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S4	AB (primary N10 care) OR "primary health care" OR "general practi*" OR GP OR nurse OR (MH "Primary Health Care") OR (MH "Physicians, Family")	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S3	AB physical AND (health* OR ill*) OR (MH "health*" OR "disease")	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S2	AB adult* OR "young adult*" OR (MH "Adult") OR (MH "Young Adult")	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S1	AB gay OR lesbian* OR bisexual* OR homosexual* OR "two spirit*" OR (sexual N5 orientation) OR (sexual N5 minorit*) OR LGB* OR transgender* OR transsexual* OR transgender OR queer* OR genderqueer OR "gender dysphoria" OR "gender identity disorder"	Search modes - Boolean/Phrase	Rerun   View Details   Edit

Refine Results

Current Search: Boolean/Phrase: S2 AND S3 AND S4 AND S5 AND S7

Search Results: 1 - 24 of 24

1. Recommendations for cardiovascular disease research with lesbian, gay and bisexual adults. (includes abstract) Caceres, Billy A, Brody, Abraham, Chyun, Deborah, Journal of Clinical Nursing, Dec2016, 25(23/24): 3728-3742. 15p. (Article) ISSN 0962-1067

Aims and objectives The purpose of this paper is to provide recommendations to strengthen cardiovascular disease research with lesbian, gay and bisexual adults, and highlight implications for practice.

Subjects: Cardiovascular Diseases, Cardiovascular Risk Factors, GLBT Persons, Health Status Disparities, Health Promotion

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Utilizing super-atom orbitals

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Search ID#	Search Terms	Search Options	Actions
S16	S3 AND S4 AND S5 AND S6 AND S7 AND S8	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S8	S6 OR S7	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S6	S1 OR S2	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S7	AB equal* OR equit* OR disparit* OR inequal* OR barrier* OR access*	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S8	OR "EQUALITY" OR DE "EQUITY" OR DE "PARITY" OR DE "PARITY" (Social sciences) OR DE "HEALTH disparities" OR DE "HEALTH services accessibility"	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S5	OR "PRIMARY care (Medicine)" OR DE "PRIMARY health care" OR DE "FAMILY medicine" OR DE "FAMILY nursing" OR DE "FAMILY health" OR DE "PHYSICIAN (General practice)" OR AB (primary N10 care) OR "primary health care" OR "general practi*" OR GP OR nurse	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S4	OR "HEALTH" OR DE "DISEASE" OR DE "WELL-being" OR AB (physical AND health)	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S3	OR "ADULT" OR DE "YOUNG adult" OR AB adult* OR AB (young N10 adult)	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S2	AB gay* OR lesbian* OR bisexual* OR homosexual* OR "two spirit*" OR (sexual N5 orientation) OR (sexual N5 minorit*) OR LGB* OR transgender* OR transsexual* OR transgender OR queer* OR genderqueer OR "gender dysphoria" OR "gender identity disorder"	Search modes - Boolean/Phrase	Rerun   View Details   Edit
S1	OR DE "LGBT men" OR DE "LGBT people" OR DE "SEXUAL minority men" OR DE "HOMOSEXUALITY" OR DE "LESBIANS" OR DE "MALE homosexuality" OR DE "MEN who have sex with men" AND DE "LGBT people" OR DE "SEXUAL minority men" OR DE "LESBIANS" OR DE "BISexuals" AND DE "TRANSgender people" OR DE "TRANSsexuals" OR DE "Transgender people" OR DE "GENDER-queer people" OR DE "TRANSSEXUALS" OR DE "GENDER identity disorder"	Search modes - Boolean/Phrase	Rerun   View Details   Edit

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Search ID	Search Terms	Search Options	Actions
510	S1 AND S4 AND S5 AND S8 AND S9	Search modes - Boolean/Phrase	View Results   View Details   Edit
59	S4 OR S7	Search modes - Boolean/Phrase	View Results   View Details   Edit
58	S1 OR S2	Search modes - Boolean/Phrase	View Results   View Details   Edit
57	All equal OR equal OR equal OR equal OR equal OR equal	Search modes - Boolean/Phrase	View Results   View Details   Edit
56	DE "EQUALITY" OR DE "EQUITY" OR DE "FAIRNESS" OR DE "PARITY (social sciences)" OR DE "HEALTH (superlative)" OR DE "HEALTH (service accessibility)"	Search modes - Boolean/Phrase	View Results   View Details   Edit
55	DE "PRIMARY care (Nursing)" OR DE "PRIMARY health care" OR DE "FAMILY medicine" OR DE "FAMILY health" OR DE "PHYSICIAN (general practice)" OR AB (primary health care) OR (primary health care) OR (general practice) OR GP OR nurse	Search modes - Boolean/Phrase	View Results   View Details   Edit
54	DE "HEALTH" OR DE "DISEASES" OR DE "WELL-being" OR AB (physical AND health)	Search modes - Boolean/Phrase	View Results   View Details   Edit
53	DE "ADULTS" OR DE "YOUNG adults" OR AB adult OR AB (young N3 adult)	Search modes - Boolean/Phrase	View Results   View Details   Edit
52	AB gay OR lesbian OR bisexual OR homosexual OR two spirit OR (sexual N5 orientation) OR (sexual N5 minor) OR LGBT OR transgender OR transsexual OR bigender OR queer OR genderqueer OR (gender dysphoria) OR (gender identity disorder)	Search modes - Boolean/Phrase	View Results   View Details   Edit
51	DE "GAY men" OR DE "GAY people" OR DE "BISEXUAL minority men" OR DE "HOMOSEXUALITY" OR DE "LESBIANS" OR DE "MALE homosexuality" OR DE "MEN who have sex with men" AND: DE "LGBT people" OR DE "SEXUAL minority women" OR DE "LESBIANS" OR DE "WOMEN" AND: DE "TRANSGENDER people" OR DE "TRANSGENDER" OR DE "TWO-spirit people" OR DE "GENDER-variant people" OR DE "TRANSGENDERISM" OR DE "GENDER dysphoria"	Search modes - Boolean/Phrase	View Results   View Details   Edit

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Result List: S17 AND S1 × +

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AND - Select a Field (option...)

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Search ID	Search Terms	Search Options	Actions
522	S17 AND S18 AND S19 AND S20 AND S21	Search modes - Boolean/Phrase	View Results (14)   View Details   Edit
521	S10 OR S16	Search modes - Boolean/Phrase	View Results (1,072,425)   View Details   Edit
520	S8 OR S9 OR S16	Search modes - Boolean/Phrase	View Results (502,470)   View Details   Edit
519	S8 OR S9 OR S7 OR S14	Search modes - Boolean/Phrase	View Results (578,441)   View Details   Edit
518	S4 OR S13	Search modes - Boolean/Phrase	View Results (8,403,216)   View Details   Edit
517	S1 OR S2 OR S3 OR S11 OR S12	Search modes - Boolean/Phrase	View Results (41,282)   View Details   Edit
516	All equal OR equal OR equal OR equal OR equal OR equal	Search modes - Boolean/Phrase	View Results   View Details   Edit
515	AB (primary health care) OR (primary health care) OR (general practice) OR GP OR nurse	Search modes - Boolean/Phrase	View Results   View Details   Edit
514	AB physical AND (health) OR (H)	Search modes - Boolean/Phrase	View Results   View Details   Edit
513	AB adult OR (young adult)	Search modes - Boolean/Phrase	View Results   View Details   Edit
512	AB transgender OR transsexual OR bigender OR queer OR genderqueer OR (gender dysphoria) OR (gender identity disorder)	Search modes - Boolean/Phrase	View Results   View Details   Edit
511	AB gay OR lesbian OR bisexual OR homosexual OR two spirit OR (sexual N5 orientation) OR (sexual N5 minor) OR LGBT	Search modes - Boolean/Phrase	View Results   View Details   Edit
510	BM Health Services Accessibility OR (BM Health Equity) OR (BM Healthcare Disparities)	Search modes - Boolean/Phrase	View Results (72,827)   View Details   Edit
50	BM General Practitioner OR (BM Physicians, Family) OR (BM Physicians, Primary Care) OR (BM General Practice)	Search modes - Boolean/Phrase	View Results (33,287)   View Details   Edit
49	BM Primary Health Care OR (BM Physicians, Primary Care) OR (BM Primary Care Nursing) OR (BM Primary Nursing)	Search modes - Boolean/Phrase	View Results (70,289)   View Details   Edit
47	BM Diseases	Search modes - Boolean/Phrase	View Results (87,276)   View Details   Edit
46	BM Health Behavior OR (BM Critical Issues) OR (BM Chronic Disease)	Search modes - Boolean/Phrase	View Results (298,134)   View Details   Edit
45	BM Health	Search modes - Boolean/Phrase	View Results (23,121)   View Details   Edit
44	BM Adult OR (BM Young Adult) OR (BM Middle Age)	Search modes - Boolean/Phrase	View Results (8,887,877)   View Details   Edit
43	BM Gender Dysphoria	Search modes - Boolean/Phrase	View Results (148)   View Details   Edit
42	BM Sexual Orientation OR (BM Transgender Phenomena)	Search modes - Boolean/Phrase	View Results (1,916)   View Details   Edit
41	BM Homosexuality, Female OR (BM Homosexuality, Male) OR (BM Homosexuality) OR (BM Bisexuality)	Search modes - Boolean/Phrase	View Results (26,382)   View Details   Edit

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Appendix B: Standardised Data Extraction Form

Data to be extracted	Notes
<b>Study Title</b>	
<b>Author (Year)</b>	(Primary author)
<b>Peer reviewed journal article?</b>	(if no, exclude)
<b>Primary research?</b>	(if no, exclude)
<b>Includes psychological barriers?</b>	(if no, exclude)
<b>Focussed on primary healthcare?</b>	(If no, exclude)
<b>Primarily sexual/mental health focus?</b>	(if yes, exclude)
<b>Setting</b>	Town/City/State, Country
<b>Study aims</b>	As stated by author
<b>Methodology/ies used</b>	Qualitative/Quantitative/Mixed
<b>Sample size and representativeness of sampling</b>	Quantitative studies
<b>Epistemological framework</b>	Qualitative studies
<b>Data collection method</b>	i.e. self-report v objective indicators (e.g. clinical indicators such as blood pressure, or attendance of appointments in audits)
<b>Analysis</b>	Robustness/appropriateness (for qualitative studies, congruence with epistemology and aims)
<b>Author reflexivity</b>	Qualitative studies
<b>Sample characteristics</b>	Sexuality (self-identified, number of participants in each category) Gender (self-identified, number of participants in each category) Ethnicity (number of participants in each category), Age range SES of participants (number of participants in each category) (all studies)
<b>Barriers (domain) using TDF</b>	(use coding framework)

<b>Overall methodological quality rating</b>	(number)
<b>Any additional considerations that could impact methodological quality rating</b>	(comments)

Appendix C: More detailed quality analysis using MMAT (Pluye et al., 2011)

Authors	Study Design	Clear research objective	Method for addressing objective	Recruitment strategy (quality rating)	Response rate	Appropriate sample	Measures	Analysis
<b>Elliott, Kanouse, Burkhart, Abel, Lyratzopoulos, Beckett et al. (2015)</b>	Cross-sectional survey	√	√	Population survey √	39% X	√	Sexual Identity only X Health status √ Trust and communication √	Appropriate model √ Weighted analysis √ Controlled for confounds √
<b>Adams, McCreanor &amp; Braun (2013)</b>	Qualitative focus group interviews	√	√	Advertising in local gay press, venues, events & websites, Snowball sampling √	Unknown	√	√	Epistemology √ Wider context √ Researcher influence √
<b>Bjorkman &amp; Malterud (2007)</b>	Qualitative interviews	√	√	Web-based advertising (moderate)	Unknown	√	√	Epistemology √ Wider context √ Researcher influence

								(partially)
<b>Edwards &amp; van Roekel (2009)</b>	Qualitative interviews	√	√	Social network for LBQ women √	Unknown	√	√	Epistemology √ Wider context √ Researcher influence X
<b>Law, Mathai, Veinot, Webster &amp; Mylopoulos (2015)</b>	Qualitative interviews	√	√	Advertisements in local community centre for LGBTQ adults (moderate)	Unknown (Transgender adults possibly dissuaded by focus on LGBTQ adults)	√	√	Epistemology √ Wider context (partially)

Appendix D: Coding Schedule using the Theoretical Domains Framework (Cane et al., 2012)

Domain	Constructs [24]	Application to primary care setting	Examples/ Rules
<b>1. Knowledge</b>	Knowledge (including knowledge of condition /scientific rationale), Procedural knowledge, Knowledge of task environment	Knowledge of physical healthcare issues that may particularly impact LGBTQ adults (i.e. health disparities, impact of hormonal/surgical treatments undertaken by some gender minorities for gender reassignment); how to implement appropriate care (e.g. screening and assessments); impact of social stigma on help-seeking behaviour in this group	
<b>2. Skills</b>	Skills, Skills development, Competence, Ability, Interpersonal skills, Practice, Skill assessment, Coping strategies	How skilled primary care professionals (PCPs) are in communication and establishing a doctor-patient relationship. Competent and skilled in examination, weighing of information appropriately for diagnosis and treatment of conditions, as well as onward referral for specialist treatment where appropriate	
<b>3. Professional role and identity</b>	Professional identity, Professional role, Social identity, Professional	The extent to which PCPs believe it is part of their role to provide specialist care and	

	boundaries, Professional confidence, Group identity, Leadership, Organisational commitment	support to LGBTQ adults or treat them in the same way as other patients; how this may be impacted by their social identities (e.g. religious identities) and professional confidence in knowledge and skills	
<b>4. Beliefs about capabilities</b>	Self-confidence, Perceived competence, Perceived behavioural control, Beliefs, Self-esteem, Empowerment, Professional confidence	PCP confidence in knowledge and understanding of LGBTQ identities and health needs and ability to meet these; perceived competence by LGBTQ adults, perceived competence in providing appropriate response to self-disclosure of LGBTQ identity and ability to establish/maintain a good doctor-patient relationship	If it is the healthcare professionals' perception of how they are perceived by LGBTQ adults regarding their skills, confidence, knowledge, ability, commitment then code as "Domain 12- Social influences (social pressure) NB: If rating by LGBTQ adults rate under Domain 4 – beliefs about capabilities
<b>5. Optimism</b>	Optimism, Pessimism, Unrealistic optimism, Identity	The confidence of LGBTQ adults that their general healthcare needs will be met by PCPs; confidence of PCPs that they will be able to meet these needs	
<b>6. Beliefs about consequences</b>	Beliefs, Outcome expectancies, Characteristics of outcome expectancies, Anticipated regret,	The beliefs of LGBTQ adults about the benefits/disadvantages of self-disclosure to PCPs, effect self-disclosure on impact on	Where the factor results in a negative consequence code as "Domain 6 – Beliefs about consequences (Outcome

	Consequents	follow up care, consequences of self-disclosure on care and doctor-patient relationship	expectancies)” Where referral made to fear of reprisal or negative impact on care after self-disclosure code as “Domain 6 – anticipated regret”
<b>7. Reinforcement</b>	Rewards (proximal / distal, valued / not valued, probable / improbable), Incentives, Punishment, Consequents, Reinforcement, Contingencies, Sanctions	How much PCP value impact of knowledge and understanding of healthcare needs of LGBTQ adults on care provision; value PCPs and LGBTQ adults put on doctor-patient relationship and impact on care	
<b>8. Intentions</b>	Stability of intentions, Stages of change model, Trans-theoretical model and stages of change	Intention of PCPs to address heteronormativity in healthcare	Where the factor refers to PCP motivation to address behaviour code as Domain 8 – Intentions (stages of change)
<b>9. Goals</b>	Goals (distal / proximal), Goal priority, Goal / target setting, Goals (autonomous /controlled), Action planning (with relation to their intention to implement	The relative importance to PCPs of addressing heteronormativity in healthcare and meeting healthcare needs of LGBTQ adults where these may differ from heterosexuals	When refers to importance of addressing heteronormativity code as “Domain 9- Goals (Goal Priority)”
<b>10. Memory,</b>	Memory, Attention, Attention	How routinely heteronormative assumptions	

<b>attention and decision processes</b>	control, Decision making, Cognitive overload / tiredness	are made in primary care context, or PCPs take steps to avoid these in consultations; diagnostic ‘overshadowing’ (pre-occupation with LGBTQ identity when not appropriate/relevant to consultation)	
<b>11. Environmental context and resources</b>	Environmental stressors, Resources / material resources, Organisational culture /climate, Salient events / critical incidents, Person x environment interaction, Barriers and facilitators	Heteronormativity in wider healthcare context; limited availability of preferred PCPs; length of consultation time and impact on care provision and building of doctor-patient relationship	Where data refers to systemic practices impacting care code as “Domain 11 (organisational culture/climate)” If factor refers to time and resource constraints code as “Domain 11 (resources/material resources)” If references made to lack of LGBTQ (formal/informal) community resources to find a preferred practice – code as “Domain 11(resources/material resources)”
<b>12. Social influences</b>	Social pressure, Social norms, Group conformity, Social comparisons, Group norms, Social support, Power, Intergroup conflict, Alienation, Group	Impact of doctor-patient relationship and its’ psycho-social antecedents (i.e. communication, trust, rapport) on ability of PCPs to meet the healthcare needs of LGBTQ adults; social attitudes of PCPs towards	Where references are made to influence of higher management/institution on PCP attitudes and behaviour refer to as “Domain 12 (social influence)”

	identity, Modelling	LGBTQ adults; power in doctor-patient relationship	Code monitoring/accountability regarding physical healthcare disparities experienced by LGBTQ adults in practice as “Domain 12 – Social Influences (power)”
<b>13. Emotions</b>	Fear, Anxiety, Affect, Stress, Depression, Positive / negative affect, Burn-out	Emotional response of PCPs to self-disclosure of identity by LGBTQ adults	
<b>14. Behavioural regulation</b>	Self-monitoring, Breaking habit, Action planning (with relation to monitoring their habits)	Ability of PCPs to self-monitor their behaviour when handling self-disclosure of LGBTQ adults (re identity, needs, social behaviour where appropriate)	