

*Background:* Little is known about the successful experiences and positive perceptions of people with intellectual disabilities (ID) self-managing Type 2 Diabetes (T2D). This study sought to address this gap using Bandura's (1977) 'Four Sources of Self-Efficacy' as a framework of enquiry.

*Method:* Semi-structured interviews were conducted with 10 adults with ID. Interviews were recorded, transcribed verbatim and analysed using inductive and deductive thematic analysis

*Results:* Nine sub-themes were identified following analysis of the data: 1) *Mastery through knowledge*; 2) *Mastery through tools and strategies*; 3) *Mastery through autonomy*; 4) *Influence of social setting*; 5) *Positive social comparisons*; 6) *Positive and negative self-statements*; 7) *Feedback from caregivers*; 8) *Adjustment experiences*; 9) *Symptom awareness*. These were mapped onto Bandura's (1977) Four Sources of efficacy enhancement model and were consistent with its proposed mechanisms.

*Conclusion:* The Four Sources model serves as a useful mode of enquiry for exploring people with ID's experiences and perceptions of self-managing diabetes. It also confirms the appropriateness of Self-efficacy as a potential intervention component for this population. However, additional support may be required for people with ID to reflect meaningfully on their experiences and thus have a sense of self-efficacy.

### **What this paper adds**

This paper builds upon the limited existing literature on people with ID self-managing type 2 diabetes and provides a robust, qualitative account of the participants' experiences, whilst confirming some of the existing challenges, both for people with ID and their supporters. To self-manage with autonomy and overcome the difficulties of adjustment, further strategies such as training and education needs are highlighted. In addition, the meaning and relevance

of the Self-efficacy construct is evaluated in the context of people with ID self-managing T2D. This provides useful information in terms of tailoring existing mainstream T2D interventions to meet the needs of people with ID, as such programs are commonly theoretically guided by Self-efficacy. Furthermore, this evaluation provides rationale for the exploration of people with IDs' Self-efficacy in relation to other chronic diseases, such as cardiovascular disease, cancer symptoms and gastrointestinal disorders.

### **1 Introduction**

Diabetes is an international health concern contributing to 1.5 million deaths around the world. It has been reported by the World Health Organisation (WHO) that 90% of people with diabetes have type 2 diabetes (WHO, 2016). Type 2 diabetes (T2D) develops when the body is unable to produce enough insulin or when the insulin is not effective, leading to high glucose levels in the blood (Diabetes UK, 2017). Risk factors for T2D are associated with lifestyle, for example poor diet and lack of exercise, in addition to poor medication control (Scottish Public Health Observatory, 2013). Previous research has focussed on how T2D can be self-managed effectively (Davies et al., 2008). Self-management is where a person with a long-term condition controls their health themselves (Diabetes UK, 2009), and involves various lifestyle adaptations, including diet, exercise, glucose control, foot care, and following recommendations for prescribed medications.

People with Intellectual Disabilities (ID) are at higher risk of developing T2D than the general population. Systematic reviews of the ID population by MacRae et al. (2015) and by McVilly et al. (2014), reported an average T2D prevalence rate of 8.3% across 22 studies and 8.7% across 13 studies respectively, while a rate of 4.7% has been reported for the general population (WHO, 2016). This difference has been attributed to a higher tendency in people with ID for T2D risk factors such as poor diet and obesity (Melville et al., 2008), poor health

literacy (Taggart, Coates, and Truesdale-Kennedy, 2013) low levels of exercise (Yates et al., 2009) sedentary behaviours (Biddle et al., 2015) and genetic conditions such as Downs Syndrome and Prader-Willi Syndrome (Emerson and Baines, 2010). Self-management is an even greater challenge for people with ID due to additional barriers such as socio-economic inequalities (Emerson, 2005), and restricted access to services (Dysch, Chung, and Fox, 2012).

Despite these inequalities, little is known about the experiences of people with ID self-managing T2D. To date, six qualitative studies have been undertaken (Cardol, Rijken, and van Schrojenstein Lantman-de Valk, 2012; Dysch et al., 2012; Hale et al., 2011; Rey-Conde, Lennox, & McPhee, 2005; Rouse & Finlay, 2016; Whitehead, Trip, Hale and Conder, 2016). These studies have highlighted the limited understanding of self-management behaviours among this population, frustrations around restricted lifestyles, and dependence on carers. These findings are mainly negative, however Whitehead et al.'s (2016) study describes the potential for positive relations between people with ID and their caregivers when a flexible, person-centred approach is taken to T2D self-management. In the mainstream population, interventions have been successfully implemented to improve self-management skills (Davies et al., 2008; Yates et al., 2009). These are typically informed by theoretical models which address behavioural change. However, other than Cardol et al. (2012a), who used Leventhal's Illness Perceptions model to explore participants' understanding, and Whitehead et al.'s (2016) Negotiated Autonomy model, there are no studies which explore the use of theoretical models addressing behaviour change for people with ID self-managing T2D. Given the high prevalence and poor self-management of T2D in this population as reported in the literature, understanding behavioural change may be instrumental in the development of interventions (such as Taggart et al., 2015) which enable

people with ID to successfully modify their lifestyles. Therefore, evaluating the appropriateness of such models for this population is an important step.

A consistently applied model in mainstream T2D models is Self-efficacy, described as the belief in one's ability to successfully perform a behaviour (Bandura, 1977). Bandura proposed four sources of efficacy enhancement; "*Mastery of Experiences*", "*Vicarious Experiences*", "*Verbal Persuasion*", and "*Physical/Emotional Arousal*". These have been successfully used to inform mainstream T2D intervention techniques (Davies et al., 2008, Yates et al., 2009) by encouraging reflection on positive self-management experiences and subsequently building confidence. However, the Four Sources model has not been explored in relation to people with ID self-managing T2D. Rouse and Finlay (2016) reported that people with ID appear to construct their self-management abilities with positivity, positioning themselves as independent and competent. It is therefore important to further understand the implications of positive self-perceptions and the impact of this on self-management. The present study therefore aimed to qualitatively explore the experiences of people with ID self-managing T2D, and to inductively and deductively evaluate the appropriateness of the model for this population.

## **2 Methods**

### 2.1 Ethical approval

Ethical approval for this study was obtained through Edinburgh Napier University Research Governance Committee and a local authority ethics committee. All participants were able to provide signed consent. Participant names were transcribed as pseudonyms and identifying details, such as day service names or local recreational clubs, were removed.

## Participants and procedure

*Insert table 1 here*

Ten participants took part in this study. This size is typical of similar studies in the literature (MacRae et al., 2015). The majority were male (n=7). Age range varied from 25 to 67 (mean = 49 years). Time since diagnosis of T2D ranged between two and 30 years (mean = 9 years). Participants were recruited through day and residential services, local authority social work centres and local area coordinators (LAC). Representatives from these organisations, including senior care staff, social workers and LAC's, who acted as 'gatekeepers' and identified potential participants for the study, informally assessing their ability to reflect and communicate sufficiently for participation. Following this, easy-read information sheets and consent forms were sent out to participants via gatekeepers. Consent was reviewed with participants prior to commencement of each interview as recommended by ethical guidelines for research with people with ID (National Disability Authority, 2009).

## Interviews and analysis

Participants were interviewed either at a day-centre or a home/residential setting. Two of the participants were accompanied by carers for the interview. Interviews were semi-structured, which enabled flexibility to explore areas of interest to participants. Each lasted under one hour, which is typical for people with ID due to barriers to communication (Beail and Williams, 2014). The interview schedule was developed with questions structured around Bandura's (1977) Four Sources model. This model was selected on the basis of its existing application to mainstream interventions such as the widely-implemented DESMOND

program (Davis et al., 2008), which has been adapted for people with ID (Taggart et al., 2015). Components of the model were contextualised for self-management of T2D and provided themes of enquiry including:

- *Mastery of Experiences*: Positive past T2D self-management experiences
- *Vicarious Experiences*: Learning how to self-manage T2D through observing peer experiences
- *Verbal Persuasion*: The importance of positive self-feedback, as well as from health professionals, regarding self-management of T2D
- *Emotional/ Physiological Arousal*: Confidence from recognising symptoms of T2D

Examples of the questions are provided in *Supplementary Materials 1*. The analysis was theoretically driven based on Bandura's (1977) Four Sources model. A latent level of analysis was used as it was necessary to interpret some statements due to communication difficulties. An inductive method guides a data driven approach in which the participants' experiences are represented (Braun and Clarke, 2006). This approach guided the initial phases in which codes were generated to reflect these experiences. A deductive approach serves the purpose of evaluating an existing theory in a different population (Hsieh and Shannon, 2005; Vaismoradi, Turunen, and Bondas, 2013). This guided the latter phases in which coded themes were organised into the constructs of Bandura's (1977) Four Sources model.

Although Bandura's framework strongly guided the interviews and analysis, the researcher strived to accurately represent the views of the participants. To ensure this, a second coder reviewed the codes and early themes, prior to these being mapped onto the framework. In addition, themes were developed using codes which contradicted, as well as supported, Bandura's model. This balance helped avoid a bias towards aligning the

participants' responses towards the model's mechanisms. Finally, the researcher drew upon his background in social care to support participants to express their own reflections and opinions, as well as obtaining contextual background information from paid carers and family members.

Each interview was audio recorded, transcribed verbatim and coded using Braun and Clarke's (2006) coding procedure. This involved a six phase guidance to analysis which included:

1. Familiarisation with data through transcription, multiple readings and note taking
2. Inductively generating initial codes from descriptions which were of importance to participants. This involved a degree of interpretation by the researcher in order to represent any experiences that participants had struggled to articulate
3. Searching for themes, where initial codes were grouped together by similarity, and organised into potential themes
4. Reviewing themes, which involved refining 'candidate themes' from the previous phase. At this stage, validity checks were carried out by the second author for accuracy, consistency and agreement of themes
5. Defining and naming themes, where analysis is organised into a narrative structure with accompanying descriptions. These themes are discussed in their own right as well as in relation to each other. At this deductive stage, the themes were mapped onto Bandura's (1977) Four Sources model. Each of the model's constructs contained supportive or contradictory themes, which enabled discussion of their relevance to people with ID self-managing T2D

6. Producing the report which is described in the results section.

## **Results**

### Overarching themes

Nine sub-themes were extracted from the data and mapped onto Bandura's Four Sources of Efficacy model. These are presented in *Figure 1* below. The "Mastery of Experience" sub-themes describe how a sense of competence in T2D self-management was obtained in the areas of knowledge, mastery through tools and strategies, and autonomy. "Vicarious Experiences" sub-themes describe the importance of social setting and social comparisons in regard to modelling the healthy lifestyle behaviour of others. "Verbal persuasion" includes sub-themes relating to the participants' positive self-feedback and feedback from others. The sub-themes included in "Physical/Emotional Arousal" describe the experiences of loss and symptom awareness.

*Insert figure 1 here:*

### **Mastery of Experience sub-themes**

"Mastery of Experiences" describes confidence derived from successful past experiences (Bandura, 1977). In the context of the present study, the participants' descriptions of T2D self-management experiences which they perceived to be successful are presented. The majority of the participants (8/10) provided these descriptions. The



experiences are organised into three sub-themes which include mastery through knowledge, tools and strategies, and autonomy.

*Mastery through knowledge*

Participants (8/10) expressed confidence regarding diet, medication and monitoring, and diabetes knowledge. Through achieving a level of competence in these areas, the participants could speak with confidence about self-management.

For Annette, a 67-year-old woman who had lived with T2D for approximately 20 years, dietary confidence appeared to have been enhanced through attending a diabetes educational program. This had led to her seeking out a range of sugar free recipes, which she was keen to describe throughout the interview. The improvements in her diet had in turn led to weight loss, as well as to her leading a more active social life

*Annette: ...if it hadn't been for [educational program] I would've still been putting on more weight...*

Self-management confidence was enhanced through knowledge for Derek, a 45-year-old man with approximately 15 years of diabetes self-management history. In this time, Derek had used several different HbA1c readers, which measure glycated haemoglobin levels to reflect to reflect average blood glucose levels, and insulin pens, which provide a self-administered insulin injection. He seemed to enjoy that this was a domain in which he was an expert, and it was apparent that this led to competence in reading and recording his blood sugar levels.

*Derek: Now I've got a talking machine, so, you put your needles and things in there...it looks like a phone...*

In contrast, other participants demonstrated a lack of knowledge which reflected confusion over diet, a dependence on support staff for medication control, and a poor understanding of exercise. Gordon, a 44-year-old male with an unknown duration since diagnosis, appeared to have a lack of knowledge regarding what constitutes exercise and appropriate levels of exercise. He described minimal amounts of walking when asked about exercise, however then later discussed friends from his Zumba class when describing social activities.

*Gordon: Ohhh, well, I only do a wee bit of walkin' see as far as the door. But I, I'm ok...*

#### *Mastery through tools and strategies*

This sub-theme describes the tools and strategies participants used to overcome barriers to self-management such as visual and memory impairments, typical in people with ID. These tools enabled some of the participants (6/10) to master self-management skills, particularly in the areas of medication control and keeping to medical appointments. For some participants, visual impairments and literacy issues were overcome by using large print. Derek had previously stated that he had poor eyesight, which he attributed to diabetes. His use of a large diary helped to offset this difficulty.

*Derek: ...Some people got a really small diary ken, three times smaller than that. I like to keep it big so that I don't need a magnifying glass.*

Derek seemed proud of his ability to keep records and was keen to demonstrate pages from the diary. Other participants used tools to avoid forgetting appointments and medication routines. Annette and Frankie both emphasised the importance of using calendars, demonstrating this by presenting them and describing upcoming events. In

addition, medication boxes were used to facilitate medication adherence. Frankie also described overcoming difficulties in finding his way to the doctor for diabetes check-ups. By using a consistent route and building a sense of familiarity, he was able to overcome anxiety about getting lost.

*Frankie: At first, I was wary at first. But, as the time went on, to me it's just a piece of cake.*

For other participants, strategies were used to overcome dietary frustrations. Having a weekly 'treat' seemed to help with the adjustment to dietary changes. For Iain, who expressed resentment over living with others who did not have a restricted diet, this involved having a weekly takeaway:

*Iain: Always have my Chinese on a Saturday. I couldn't cut that out.*

These tools enabled the participants to overcome T2D self-management barriers such as cognitive impairments associated with having an ID, as well as coping with frustrations around loss.

### *Mastery through autonomy*

The participants' (4/10) success of "Mastery through Autonomy" was dependent on relationships with those in support networks, including paid and unpaid caregivers, who could facilitate or control diabetes self-management. Autonomy was therefore achieved through both the acceptance or rejection of support from others.

Several participants described independently attained knowledge, including Sam, Frankie and Derek. Each stated that they were given little information following their diabetes diagnosis, and that they had needed to learn by themselves, through trial and error.

*Frankie: Aye well I've sort eh. sort of learned through the hard way eh?*

For Sam, this was followed later with statements which suggested a rejection of social support. Sam had experienced some difficulties in the past with medication adjustment. He described an experience where he felt that his stress levels interacted with his medication, leading to a hypoglycaemic episode, which occurs when blood glucose levels reach a low point resulting in sweating, dizziness and fatigue (Diabetes UK, 2017). He blamed this on the lack of information provided by his doctor at the time:

*Sam: The only trouble is.. doctors. I wish they would give you more information about tablets...*

Sam also described situations involving discussions with his doctor. These were in regard to smoking cessation and medication control, and in both Sam positioned himself as the expert, suggesting that he was better informed:

*Sam: ...the doctor was sayin', ah its ok, dinnae worry about it, just reduce it by 2 units for days blah blah blah. But, I looked at the figures and I knew what I needed.*

For Daniel, autonomy was facilitated by his support worker. Daniel was a 53-year-old man, who had also been diagnosed two years before. He described good intentions towards controlling his diabetes through diet and exercise, but also described this being struggle for him. However, his support worker had helped him to make healthier decisions and choices, as the following example demonstrates:

*Daniel: ...we got some of these muesli bars, and we decided to put them in my safe, so I don't eat them all in one go.*

These three areas of experience provided the participants with a sense of confidence in their ability to self-manage with independence. Confidence could also be attained through the influence of others, as the following theme suggests.

### **Vicarious Experiences sub-themes**

“Vicarious Experiences” describes confidence from observing success in peers and modelling this behaviour (Bandura, 1977). The present sub-theme, which represents 4/10 of the participants, describes the limitations for social modelling opportunities in the participants' lives, as well as their descriptions of being a positive influence on others. Finally, there are descriptions of participants modelling people without ID, who are an influence on the participants' lifestyles.

#### *Influence of social setting*

The social settings of some participants in this study (3/10) were sometimes detrimental to self-management, particularly in regard to diet. Participants who lived in shared accommodation were often surrounded by other people with ID who did not have diabetes, and thus no dietary restrictions. This led to frustration, rather than providing positive examples for social modelling. Iain described finding this particularly difficult during special occasions, for example when cake was handed out. These occasions, where self-restraint was challenged by temptation, appeared to have had a negative impact on his acceptance of having developed diabetes:

*Iain: ...especially if somebody's got a birthday in here, ey, with a birthday cake. I [can't] take a bit cos of my diabetes*

However, in other areas of self-management the influence was more positive. Sam described a reciprocal caring relationship in which Mary, his wife, could recognise in him the early symptoms of a hypoglycaemic episode and Sam could subsequently adjust his insulin. In turn he, could help with her own adjustment:

*Sam: Well, looking after mine, and looking after hers, I'm able to help her, she knows roughly when I'm in the early stage of a hypo, I don't know how but she does. And um.. eh.. I'm able to adjust my insulin, plus I'm able to adjust hers... if it needs adjusting.*

The influence of setting was also described by several participants (5/10) in relation to exercise, such as Gavin who described going hillwalking as part of his day service activities, and Annette who had participated in a sponsored walk. Daniel described his caregivers supporting him to moderate his pace when going for walks so that he was able to do so without becoming fatigued:

*Daniel: But eh, Ali and Pawel is getting me to walk at a pace which is comfortable. Because I used to go "wheesht wheesht," know what I mean?*

#### *Positive social comparisons*

Although the participants could not provide positive examples of social modelling from their peers, Annette's attendance at a structured education program had enabled her to meet other people with ID who were self-managing T2D. She described a situation in which she was the positive influence on a fellow attender, who had expressed reservations about making dietary changes:

*Annette: ...I met a girl when I was at [training location], and she said I can't try anything like that, try and change my diet... then I said, I've got a sample with me, if you [want to] try it.*

Social modelling was also positive when comparisons were made by people with ID (2/10 participants) and their caregivers. In this sense, role models provided examples of healthy lifestyle approaches. Gavin's day service included cookery workshops and outdoor activities. It was evident that Gavin's workshop leader was a positive influence on his wellbeing, in terms of dietary choices and physical activities:

*Gavin: I like making [healthy foods] with Stefano... It's [good for you] when you make it with Stefano! I just like going for walks with people.*

### **Verbal Persuasion sub-themes**

Examples of "Verbal Persuasion", which describes confidence from positive feedback (Bandura, 1977), are presented below as self-statements from the participants (3/10) in relation to their T2D self-management, and of participants (3/10) who appeared to value feedback provided to them by their caregivers.

#### *Positive and negative self-statements*

This theme describes the self-statements participants gave, which offered insight into their self-perceptions and self-feedback. There were positive and negative statements, which reflected varying levels of confidence in regard to self-management skills. These were mainly related to dieting and exercise, highlighting the participant's beliefs about their ability

to make changes. Derek, although using a humorous tone, described himself as a “bad diabetic” and unable to make dietary changes. In this sense, he seemed resigned to this being part of who he was:

*Derek: I'm one of these bad diabetics that's what it is.*

These statements matched Derek's earlier descriptions of his struggle to control his diet, which may therefore suggest that his diet was influenced by his self-perception. In contrast, it was evident that Daniel believed in his ability to change, despite his being aware of how difficult the discipline of adhering to this could be. Daniel was accompanied by his support worker, who reminded him of the habits he might revert to, including excessive snack consumption, not exercising and forgetting medication:

*Daniel: It is hard but I can do it. You know I'm gonnae try and do that...*

Mary, a 58 year old woman with mild ID who had been diagnosed with T2D 15 years prior to interview, also saw herself as able to change. At the time of the interview Mary was in hospital due to several weight related complications. She was aware of the debilitating effect this was having on her life, mentioning that she was no longer able to put on footwear without assistance. However, she intended to use an earlier photograph of herself, as a motivator to lose weight:

*Mary: ... And I'm gonna have it framed and I'm gonna sit and look at it, and focus my mind onto losing the weight again.*

Having the intention to carry out this goal suggests that Mary gave herself positive feedback despite the difficulty of her present circumstances. She saw herself as capable of making dietary improvements, though it is unclear the extent to which Mary would overcome barriers to this, such as the habits which led to her weight gain. Similarly, it is not clear from Daniel's comment how he will accomplish change.



*Feedback from caregivers*

This theme describes “*Verbal Persuasion*” in the sense of taking encouragement from influential others, such as carers and health professionals, who had offered positive feedback. The majority of the participants were able to recount experiences where they had taken encouragement from positive feedback, despite there being some ambivalent attitudes to health professionals, as highlighted in “*Mastery through Autonomy*”. Sam had described episodes where he was better informed than his doctor about his health. However, he valued the encouragement that his diabetes nurses could offer him regarding weight loss:

*Sam: Yeah, it's quite a boost to my system, when they give me a positive feedback, from something that I've done.*

Frankie described himself as having a good relationship with the nurses he saw at his diabetic clinic. He expressed that keeping to these appointments were important to him because of this:

*Frankie: Aye, aye... they make you happy some of the times and that, because they're cheerful.. and they're all right with me and I'm alright with them. And I think they're happy with me cos I, I turn up for my appointments and that eh?*

As the majority of the participants were independent, there were fewer examples of relationships with caregivers and their feedback. When Gavin was asked what he enjoyed about hillwalking, it appeared that the positive feedback from one of his caregivers was a motivational factor:

*Gavin: I like walkin' up the hills...Sheona says I'm good at walkin'...*

### **Physical/Emotional Arousal sub-themes**

“Physical/Emotional Arousal” describes confidence from physiological or emotional feedback (Bandura, 1977). The sub-themes below describe the emotional experiences of the participants (3/10) in regard to their experiences of adjusting their lifestyles in order to self-manage their T2D. Accounts of physical feedback were also given in the form of symptom recognition for two of the participants.

#### *Adjustment experiences*

The emotionally turbulent experiences of some of the participants are reflected in this theme. These are in relation to the lifestyle adjustments they faced following their diabetes diagnosis. Some participants expressed frustration and resentment relating to a sense of loss in regard to what they could do and where they could go. This may have impacted on a lower sense of self-efficacy.

Sam’s sense of loss was expressed regarding his no longer being able to drive certain vehicles and subsequently ability to work. This was due to the risk of having a hypoglycaemic episode. Following this he had tried to train as a mechanic but had suffered from a similar experience, leading to him being told he could not work. He recounted this, and described the frustration he experienced following it:

*Sam: ... We'll put you on long term unemployment. And ey it's a bit of a bugbear to me, it's like a thorn in the flesh.*

Sam also felt that his condition prevented him from being able to do exercise, which he was aware would be beneficial to his diabetes management, describing this situation as a “catch 22”. Other participants such as Iain and Daniel expressed frustration at their dietary restrictions, and of no longer being able to eat the things they enjoyed:

*Daniel: What I dinnae understand is.. I can.. I can stop the temptation of going to the chippie. But the sugar...*

However, despite being aware of the loss, some participants appeared to feel that they had moved on from this and had successfully adjusted to their new lifestyle. Janie was a 25-year-old woman who had been diagnosed two years before. Although she needed assistance from her support worker to participate in the interview, Janie was able to reflect on her experience of adjustment positively when asked if she had experienced it as difficult:

*Janie: No it doesn't bother me. I'm used to it the now.*

Making these adjustments and thus reducing frustration may have enabled participants to have a great sense of Self-efficacy in their self-management.

### *Symptom awareness*

Symptom recognition was also an important source of confidence in self-management for some participants, for example knowing how and when to respond to signs of a hypoglycaemic episode. For Frankie, this involved recognising the sensation of feeling tired due to low blood sugar levels:

*Frankie: I know the uh, I know the symptoms. Oh aye, I know the symptoms. I know when to stop [to respond], I know when I feel like that.*

Mary and Sam had also described the importance of recognising and responding to symptoms. These sensations acted as trigger warnings for participants, and recognising them provided them with a sense of control over the physiological effects associated with having diabetes.

### **4 Discussion**

The aims of this study were to explore the experiences of people with ID self-managing T2D using Bandura's (1977) Four Sources of Efficacy Information as a mode of enquiry and to assess the meaning and importance of the model's constructs for people with ID. The model provided a useful framework for the nine identified sub-themes, which in turn provided support for its use with people with ID. These findings are summarized in relation to each of the Four Sources below.

The descriptions of task mastery in "*Mastery of Experiences*" highlight the areas in which people with ID may potentially enhance their confidence in diabetes self-management, and interventions such as Taggart et al. (2015) which encourage participants to reflect on areas in which they have been successful may therefore be appropriate for this population. However, several challenges were also apparent, such as engaging in regular exercise and medication management. There was also a sense of confusion over what constitutes a healthy diet for some participants. It is possible that assertions of competence may not be a true reflection of these self-reported diabetes management skills, some of which may have been over-estimated. This would be consistent with the findings of Salaun, Reynes, and Berthouze-Aranda (2013), who found that Positive Illusory Bias (PIB) was an important factor in the self-perceptions of adolescents with ID undergoing a physical activity program. In a discursive analysis of people with ID self-managing T2D, Rouse and Finlay (2016)

reported conflicting constructions of competence, where empowered positions were taken despite dependence on caregivers. Future studies may benefit from the use of proxies, such as carers or family members, who could corroborate statements. However, the perceptions of the participants in the present study may yet have contributed to the participants' sense of Self-Efficacy, regardless of the accuracy.

“*Vicarious Experiences*” was found to be important to some participant's self-management confidence. Social modelling opportunities are not always possible for people with ID self-managing their diabetes, since shared living situations do not always provide examples of others with diabetes (Emerson and Baines, 2010). However, some participants' experiences suggest that where there is opportunity, people with ID may potentially enhance their efficacy in self-management through learning from others. Group-based interventions which facilitate positive peer comparisons may therefore be of benefit. However, the extent to which people with ID see themselves as the same as or different from people without ID when making social comparisons should be considered. Examples of social modelling may also be provided by caregivers and comparisons, which may be of higher value to people with ID (Paterson et al., 2012).

The participants made statements about themselves which may give an insight into their “*Verbal Persuasion*”. This feedback was both positive and negative and could reflect varying levels of self-confidence in self-management skills, as well as intentions to change. As with “*Mastery of Experience*”, some additional support from proxies may have helped to confirm or contest these statements. The importance of feedback from caregivers and health professionals was also highlighted, though this may also be subject to the participants' sense of autonomy, which was highlighted in “*Mastery through Autonomy*”. Cardol et al. (2012b) reported that attitudes of caregivers reflected a dilemma between enabling a sense of autonomy and ensuring competence in T2D self-management. It is therefore important to

consider that autonomy may be negotiated across situations, as highlighted by Whitehead et al. (2016). Despite this, the overall impression given by the participants was that *Verbal persuasion*, from themselves and others, may be a source of Self-efficacy enhancement.

Regarding the final of component in Bandura's efficacy enhancing model, "*Physical/emotional arousal*", the adjustment experiences of the participants were not wholly positive and reflected the need for support in coping with lifestyle changes. This is consistent with the findings of Hale et al. (2011) and Cardol et al. (2012a), who reported people with ID's frustrations at loss of autonomy due to adherence to dietary and exercise regimes. This may have led to a low sense of self-efficacy, although some participants had made the adjustment and were therefore more at ease with their situation, potentially offering them a sense of "*Mastery of experiences*".

Symptom recognition and acting accordingly was a clear indicator of participant's response to physiological arousal, and as such was a source of Self-efficacy enhancement. This aspect of the Four Sources model can be extended, as some participants drew confidence from recognising symptoms in others, rather than just in themselves. Therefore, there is potential for facilitating the process of symptom recognition for people with ID to enhance confidence in diabetes self-management. Future interventions may benefit from supporting people with ID to develop this recognition following diagnosis, for example by using reflective diaries or through discussion with peers, as with the buddy system suggestion in Hale et al. (2011).

As to the overall usefulness of the model in supporting people with ID to self-manage T2D, it may be that some components are more valuable than others. Bandura (1977) proposed that "*Mastery of Experience*" is the most efficacious component of Self-Efficacy, and has accordingly been given importance in the development of mainstream interventions (Davies et al., 2008). However, given the additional social-support needs of people with ID,

strong emphasis should be given to "*Vicarious Experiences*" and "*Verbal Persuasion*" when considering the development of efficacy-enhancing resources for this population. With regard to the latter, it is important to continue to ensure that the autonomy of people with ID is upheld as far as possible, and that persuasion does not become acquiescence.

This study has taken a rigorous approach to exploring the T2D self-management experiences of people with ID. There was strong theoretical basis, and a robust, clearly delineated methodology. It is important to note limitations. Firstly, recruitment was restricted by the willingness and resources of gatekeepers to highlight and approach people with ID to take part, which meant that neutrality of approach could not be fully ensured; it is possible that biases from gatekeepers about the value of the study could influence the decision to take part. An easy read information sheet was sent out to Gatekeepers so that they could in turn send to participants, or assist with reading, which may have helped to reduce any recruitment biases through consistency of approach.

A sample size of 10 is acceptable for a qualitative study of this scale; studies with people with ID self-managing T2D range from N=4 (Dysch et al., 2012) to N=14 (Hale et al., 2011). A larger sample may have compensated for communication difficulties in some participants. However, as transcripts were analysed concurrently, it was possible to achieve data saturation as no new themes were identified from later interviews.

### **Conclusion**

The Four Sources model provided a useful framework for enquiry in the present study on people with ID self-managing T2D. The important self-management experiences for the participants, were inductively represented, then organised into the four components of the model. However, in order for the model to be used as the theoretical basis for interventions or structured educational programs aimed at people with ID, additional support is required,

primarily in the area of facilitating self-reflections. This may be achieved through the use of proxies, or tools such as reflective diaries, thus enabling a clearer sense of where strengths are and how these can be developed further.

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