

**A qualitative exploration of participants' experiences of taking part in a walking programme: perceived benefits, barriers, choices and use of intervention resources.**

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**Key words:**

Walking, physical activity, intellectual disabilities, qualitative, participant experiences, inequalities.

**Abstract**

**Background:** Adults with Intellectual Disabilities (ID) experience significant inequalities and tend to be more sedentary and less physically active than the wider population. Walking programmes are an effective way to increase physical activity (PA) but have not been used in studies involving adults with ID.

**Method:** 19 adults with ID participated in semi-structured interviews or focus groups exploring their experiences of taking part in a walking programme (Walk Well). Data were coded using thematic analysis.

**Results:** Four overarching themes emerged: perceived benefits of taking part in the programme, perceived drawbacks/ barriers, walking choices and using the Walk Well resources. Whilst there was not a significant increase in walking for all, the participants reported positive experiences of taking part in the programme. Self-monitoring proved difficult for some, particularly reading the daily step-count recorded on the pedometer and writing it in the diary. Carers also played an important role in facilitating and preventing behaviour change in adults with ID.

**Conclusion:** Additional barriers prevent many adults with ID from participating in PA.

Capturing participant experiences provides important information for designing effective and equitable health improvement programmes.

## **Introduction**

Evidence suggests that adults with intellectual disabilities tend to have poorer health than the general population (Cooper et al., 2007, Emerson, 2005, Martínez-Zaragoza F, 2016, Cocks et al., 2016). They also lead more sedentary and less physically active lifestyles (Temple, 2007, Temple and Walkley, 2007, Finalyson et al., 2011, Dairo et al., 2016, Bergstrom et al., 2013) and have higher rates of obesity (Melville et al., 2008, Bhaumik et al., 2008, Melville, 2016). Comparison studies, internationally, have shown adults with intellectual disabilities generally walk at lower intensity, frequency and duration, compared to the general population (Finalyson et al., 2011, Stanish et al., 2006). As such, the promotion of healthy lifestyles in this population has been recognised across the globe, with a growing number of researchers designing interventions to increase physical activity (PA).

Regular walking has been shown to have a wide-range of health benefits, including reductions in body fat, BMI and diastolic blood pressure and increases in VO<sub>2</sub>max (Murphy MH, 2007, Hanson and Jones, 2015), resting heart rate, total cholesterol and depression scores (Hanson and Jones, 2015). As walking is an effective and sustainable form of PA which can be undertaken by very sedentary or inactive populations, walking programmes are becoming increasingly popular as a way to increase activity levels (Williams et al., 2008). Research suggests walking interventions can effectively increase physical activity in low-active non- intellectual disability populations (Fitzsimons et al., 2012) and there have been a number of studies which have examined if health intervention programmes can increase PA levels, motivation and/or other health behaviours in adults with intellectual disabilities

(McDermott et al., 2012, Ewing et al., 2004, Mann et al., 2006). However, prior to the recently published study by the authors (Melville, 2016), only one pilot study of a walking intervention involving adults with intellectual disabilities has been published (Moss, 2009), with no qualitative data included. As such, the experiences of adults with intellectual disabilities taking part in walking programmes remain unknown. Importantly, carrying out qualitative research with individuals with intellectual disabilities allows participants the opportunity to talk about their experience of taking part in a study. Arguably, this is particularly meaningful in the context of a randomised control trial (RCT), where traditionally expertise is seen to reside with the researchers rather than the 'subjects'. Therefore, unlike the main RCT (described below), the qualitative element of this study positions the participants as the experts, of their own experiences.

There is some debate about the most effective way to carry out qualitative research with vulnerable individuals. Focus groups can be more effective than face-to-face interviews and questionnaires as individuals may not have thought about how they feel and often do not form opinions in isolation (Hildebrandt, 1999). Individuals may also be more willing to discuss their views with peers, rather than one to one with a researcher (Gratton, 2004). Conversely individual interviews can alleviate social pressures of speaking in front of others and reduce participants to voice a peer group decision, to avoid ridicule or embarrassment. Therefore, offering participants an element of choice about how they are interviewed should be considered when working with adults with intellectual disabilities.

Qualitative research exploring individuals without intellectual disabilities experiences of walking programmes provides useful information about physical, social and environmental influences on walking (Crone, 2007, Hunt, 2013, Normansell, 2014). This research offers valuable insights for developing more effective interventions for the general population and

indeed tailored programmes for specific sedentary populations. For example, offering pedometers to self- monitor behaviour has been shown to be an effective way to motivate participants in walking studies (Baker et al., 2010, Hunt et al.). Previous qualitative research also offers insights into the factors that can determine participants' experiences of walking programmes (Normansell, 2014). For example, the intervention itself (e.g the PA consultation, equipment provided, behaviour change techniques used) and also factors out with the research study (e.g. physical health, social benefits, weather). This information is useful in highlighting the areas or factors that are within the researchers control, that can be modified for behaviour change.

While there is a growing literature around the use of technology and visualization methods that could help people with intellectual disability understand and use an array of information (Borg et al., 2014, Parsons et al., 2015) there has be no research which has qualitatively explored the experiences and effectiveness of self- monitoring physical activity behaviour for people with intellectual disabilities.

This paper addressed this gap in the literature by providing an insight into adults with intellectual disabilities' experiences of participating in, and self- monitoring their physical activity behaviour, in the first community based RCT walking programme (Walk Well).

### **Walk Well RCT**

Walk Well aimed to support adults with intellectual disabilities in Greater Glasgow, Scotland, to be more physically active using an individualised 12 week walking programme. The objective of the RCT was to examine the effectiveness of this 12 -week behaviour change

programme to increase walking and reduce sedentary behaviour of adults with intellectual disabilities. We used a cluster randomised controlled design and recruited participants over 18 years old, with any level of intellectual disability, who were not regularly involved in physical activity from intellectual disability community-based organisations. Participants lived in a range of accommodation, some lived a home with a family member, others lived independently with carer support (from 1 hour per day to 24 hours per day depending on individual needs), and many lived in supported accommodation with other individuals with intellectual disabilities. The majority of participants in this study had paid carer support. Assessments were carried out blind to allocation. Clusters of participants were randomly allocated to the Walk Well programme or a 12-week waiting list control. Walk Well consisted of three face-to-face physical activity consultations incorporating behaviour change techniques, written resources for participants and carers, and an individualised, structured walking programme. The Walk Well intervention was designed to be accessible to people with an intellectual disability. The resources, consultation and walking plan was tailored to the individuals needs of the participant (e.g. the components of the intervention that were used, the language and interaction with participants, the amount of support give to the individual when designing the walking plan). Participants were also offered a pedometer to self – monitor steps. The primary outcome measured with accelerometers was change in mean step count per day between baseline and 12 weeks. Accelerometer data was included in the analysis if participants had worn it for at least six hours a day for at least three days a week, at each of the data collection periods. Secondary outcomes included percentage time per day sedentary and in moderate-vigorous physical activity (MVPA), body mass index (BMI), and subjective well-being. One hundred and two participants across 50 clusters were randomised. The results showed no significant between group differences in percentage of time sedentary, percentage time in MVPA or subjective well-being. This is the first published

trial of a walking program for adults with intellectual disabilities (Melville, 2016). For more information about the Walk Well RCT see (Mitchell et al., 2013, Matthews et al., 2016).

The remainder of this paper will focus on the qualitative component of the study which aims to:

1. To explore participants' experiences of participating in a walking programme, specifically the perceived benefits, barriers, choices and use of intervention resources (including self-monitoring with pedometers).
2. To investigate the factors or influences that may have impacted on their walking experiences.

## **Materials and Methods**

### ***Ethical Approval***

Full ethical approval has been granted for the study by the Scotland A Research Ethics Committee (Reference 13/SS/229). In keeping with the Adults with Incapacity (Scotland) Act 2000, a participant with capacity provided their own written, informed consent and otherwise written consent to participation was provided by the nearest relative, or welfare guardian. Informed consent to participation was provided for all participants before data collection started. Any information in the interviews that could lead to the identification of participants was removed, made anonymous, or replaced with pseudonyms to ensure the confidentiality of participants, walking group, and carers/staff leading the walks.

### ***Design***

Semi-structured interview and focus groups were used to collect information about participants' experiences. These were carried out 1-4 months after the participants had participated in the Walk Well study. Individuals who walked together as part of a service-based group (a group that was organised by their service provider and had a career leading the walk) were offered the choice to either be part of a focus group with their walking group peers, or interviewed individually. Individual interviews were carried out with individuals who walked alone (or with a carer/family member).

It is important to note that the walking advisor who was part of the study team aimed to provide motivational support and encouragement to do more physical activity through the use of a physical activity consultation. The walk well programme aimed to be tailored and flexible for the individual, rather than one fits all approach, therefore some participants preferred to walk alone, others with a carer, others in a group led by a carer or centre staff member. Essentially, the 'key ingredients' of the intervention which was the PA consultation and resources that each participant received was similar (depending on how much support an individuals required), but the walking context was flexible. Therefore, staff at the day centres were encouraged to set up walking groups that could support participants in the study to walk more, building on the PA consultation they had worked through with the walking advisor. More information about the PA consultation and resources can be found at (Mitchell et al., 2013). The day centre staff therefore made decisions about who would walk in the group and where they would walk.

Both interviews and focus groups aimed to understand participants' experiences of taking part in a walking programme, however the different approaches were used to ensure that the groups dynamics of those who walked in a group would be captured. In addition, the focus groups allowed the researcher to observe group norms and understand how the participants in

each group reacted to the views of others and defended their own views. The focus groups were self-selected by the participants who walked together. Participants were assured they did not have to take part in the focus group or interview if they did not want to. The researcher had met the participants at least 4 times prior to the interviews/focus groups. This offered the opportunity to become familiar with the participants and chat to them about their lives more generally. The researcher adopted a friendly, informal and open approach with the participants to ensure they felt at ease with her. This helped to build rapport, which is particularly important when working with vulnerable populations. At the start of the interview the researcher explained the purpose of the questions and assured participants that there was no right or wrong answer to each question. Participants were also assured that if they did not understand the question, the researcher would rephrase to try and aid understanding. Participants were also informed that it was okay if they did not know the answer to the questions. Questions were designed to be straightforward and clear. All questions were open ended and only one question was ever asked at one time (see appendix 1). This was to ensure that participants were not overburdened by the questions. If participants were struggling to articulate an answer, the researcher would try to help as much as possible. However, she was careful not to lead the participants to answer in a particular way. When transcribing and analysing the data, the data was carefully labelled to ensure only the words from the participant were reported as their own. The questions in the interviews/focus groups were not considered to be sensitive, and it is unlikely that the participants felt uncomfortable discussing their experiences of participating in the walking programme.

### ***Sampling***



Selecting participants is something which needs careful consideration when working with hard to reach or vulnerable groups. Individuals with intellectual disabilities often have limited opportunities to express their own opinions and emotions about a research study they have participated in (MacMahon et al., 2014), with carers often interviewed on their behalf (Spanos et al., 2012, Griffith and Hastings, 2014). This can however result in the carers' views being presented rather than the true participant experience. This not only has implications for the reliability of the data, but also excludes the voice of individuals with intellectual disabilities. The aim of this study was therefore to include the direct views of individuals with intellectual disabilities' experiences of participating in a walking programme.

A sampling grid was used to ensure a broad range of experiences were captured in the interviews. As the design of the RCT was a waiting list control design, or stepped design, all participants who were interviewed had participated in the walking programme. This included a mix of those who had participated in the walking programme immediately after the baseline visit (intervention group) and those who participated 12 weeks after baseline (waiting list control). Potential participants were selected based on age and change in steps walked per day, based on accelerometer data pre- and post-intervention, ranging from those whose walking had decreased to those with a significant increase in steps walked. Each focus group also included a range of age, gender and percentage change of steps walked, as shown in Table 1.

*Please place Table 1 about here*

### ***Participants***

Of the 102 participants who took part in the Walk Well RCT, nineteen were invited to participate in a semi-structured interview (N=7) or focus group (N=12). Prior informed consent was obtained in writing from all participants at the start of the RCT, and supplemented by verbal consent immediately before data collection for the qualitative study began. Participants with a range of intellectual disabilities were included in the study. Everyone in the focus groups and interviews had the capacity to understand and respond to straightforward questions. Individuals were given the option of having a carer or family member also attend the interview. One participant asked for her sister to be present for the interview. In this instance (interview 7, Heather), the researcher emphasised that it was the experiences of the individual who had taken part in the walking study that were of interest.

### ***Interviews and focus groups***

Interviews and focus groups, lasting 30-60 minutes, were carried out in participants' homes or day centres, within four months of the programme ending. When designing the interview/focus group guide, the researchers followed the Economic and Social Research Council (ESRC) approved guidelines for research with people with intellectual disabilities (Rolph, 1998). The guide was developed by the research team and comprised of general questions about walking and specific questions about the walking programme, e.g.: perceived benefits, drawbacks and impact. All participants gave permission for the interviews/focus groups to be audio-recorded. Recordings were transcribed verbatim by a member of the research team not involved in the data collection.

### ***Data Analysis***

Due to the interpretive and subjective nature of qualitative research, it is understood that those involved in the research may have some influence over the data collected. As (Yardley, 2000) argues, the researcher and participants' reactions, observations, thoughts and opinions are unavoidably embedded in the collection and analysis of the data. Therefore, in order to ensure 'trustworthiness' of the data from this qualitative study, Lincoln and Guba's (Lincoln, 1985) guidelines on data collection and analysis were followed. For example, credibility was addressed as the researcher had met with the participants at least 4 times before interviewing them (see above) and therefore has some insight into their life and participation in the programme. Transferability was ensured through the presentation of 'thick descriptions' of the findings, the use of quotes to provide context for the reader, and through the use of a sampling grid to ensure a variety of individuals were included in the qualitative part of the study.

Data analysis drew on an inductive thematic approach set out by (Braun, 2013). To enhance reliability, the transcripts were systematically coded independently by the two researchers who designed the interview/focus group guide. The second researcher had not met the participants and was an advisory member of the research team. Therefore, this provided a somewhat 'independent' perspective on the data. Both read through each transcript several times before identifying initial themes. Transcripts were re-read and themes and sub-themes refined. The researchers also searched for consistent patterns of meanings and relationships across transcripts and grouped categories together, as well as noting divergent views. This process was used until data saturation was achieved. The only difference to emerge between researchers related to overlapping sub-themes (i.e. if some could be merged into a broader theme) and this was resolved through discussion.

## **Findings**

This paper reports four main themes and eight sub-themes in participants' experiences of the walking programme. These are presented in table 2 below. Pseudonyms are used to protect the identity of participants.

\*\*\*\**insert table 2 here*\*\*\*\*\*

### **Theme 1: Perceived benefits of taking part in the project**

The first theme discusses the perceived the benefits of taking part in the walking programme. This is split into physical health gains and social and psychological health gains.

#### ***Physical health gains***

A few of the participants felt they had lost weight from taking art in the programme:

*Lewis: Things have got a lot better, he [Jamie] has lost weight, and she [Mairi] is so so. I've lost weight. So we have kept to our regime, our pedometers and our belts.”*  
*(Focus group 1)*

Some participants reported that walking relieved the symptoms of specific health conditions. For example, Lindsay found that walking reduced stiffness associated with her arthritis.

*Lindsay: ...If I sit too long in the house I end up saying to myself I need to get up and even if it is walking into the kitchen and making a cup of tea or doing your dishes or doing your washing. I have to try and do something because I get all sore if I sit too*

*long...I have arthritis and that doesn't help when it is damp weather, it makes you all sore.”(interview 5)*

While the bad weather sometimes prevented her from going out walking and relieving stiffness, Lindsay ensured she was moving around regularly indoors to prevent sore joints. Using strategies to keep active indoors was also mentioned by others. For example, Aaron used weights in his living room and Claire would often go on her exercise bike or use her ‘Mr. Motivator’ DVD.

*Claire: I go that [points to exercise bike] sometimes as well... I can actually do it during the day as well, during the day and at night time.”(interview 2)*

The use of alternative exercises to walking outdoors indicates participants’ motivation to get or stay active during the programme and the reasons given were related to weight loss, building muscle, wanting to feel better, become fitter and be less tired during the day:

*Aaron: “It [walking programme] means that I am not lying in bed half of the morning and I am also walking for the sake of it. Getting a breather and when I come back I am wide awake...Since going out places I have got used to walking a lot more and I am not so out of breath.” (Interview 1)*

### ***Social and psychological health gains***

An increase in confidence as a result of spending more time outdoors and interacting with others was mentioned by several participants. Research in the exercise psychology domain indicates a positive relationship between physical activity participation and higher levels of

self-efficacy across a range of populations (McAuley, 2000, Motl et al., 2013). This also applied to some individuals in this study:

*Researcher: "How have you been since I last saw you?"*

*Tony: "My confidence wasn't so good. Since then it has grown massively...Just being more active and more social...because when I am out I have to interact with people, so it has helped me with that...It forces me to talk to other people when I wouldn't have talked to them before." (interview 6)*

For some participants, enjoyment was enhanced by walking in the company of people they already knew. A few participants reported that they would have not felt comfortable having to get to know 'new' people in a walking group. Social support is an important enabling factor for participation in moderate-intensity physical activity in the general population (Sallis and Owen, 1999) and in exercise programmes for adults with intellectual disabilities (Millar et al., 1993, Pitetti and Tan, 1991). In the current study, individuals were given the option of walking on their own (with a parent or carer if preferred or required) or in a group at their day centre or local walking group. The results from this research confirm the importance of offering individuals a choice about who they walk with and highlights the need for considerations in setting up activities for individuals with intellectual disabilities who do not know each other.

Other psychological benefits identified by participants included having a 'more positive outlook', improved self-esteem, feeling relaxed and less tense than before. Some gained from having a sense of purpose and useful occupation, especially when this represented a change from their usual routine, sometimes perceived as boring.

*Lewis: "It pushes you to get up in the morning. If you are not working go out for a walk and back, and you're proud of yourself that you have went for that walk" (focus group 1)*

Several participants felt a sense of pride and achievement from participating in the walking programme; this is particularly important among a group of people who experience low levels of self-esteem.

## **Theme 2: Drawbacks/barriers to taking part**

### ***Adverse weather***

As supported by walking studies with other populations, the weather was seen as one of the main barriers to walking for most of the participants:

*Lindsay: "I do try and do quite a lot of walking but with this weather you can walk but it means that you are going to get wet all the time."(interview5)*

Others were put off by snow, ice and wind. However, the weather was not a deterrent for all:

*Heather: "It doesn't matter if it rains, I still go out.*

*Researcher: "That's really good."*

*Heather: "If it rains, it doesn't matter, you just go home and go for a bath."*

### ***Perceived risks***

For independent walkers, sometimes the route was set in advance by a carer or family member. This was intended to reduce any risk of getting lost, avoid busy roads or help people who were not steady on their feet. However, despite planning for walks, some participants still felt a level of risk when walking alone:

*Heather: "When I went out to walk today I just put my foot out [on the road] and I went, I shouldn't have done that because a car was coming... I done that once before and nearly got myself killed...Not now, I wait for the green man."(interview 7)*

Some individuals' level of support needs meant that someone would always be required to walk with them:

*Researcher: "So they [carers] take you to the park, Martin. Do you like going to Tollcross Park walking?"*

*Martin: "A wee bit...Every time when someone gets up I'm away ahead."*

*Researcher: "Are you away ahead of everyone?"*

*Martin: "Yes, - but I'm not allowed."*

*Hazel: "He would go missing."(focus group 3)*

In this case, the risk of going missing, or getting lost was recognised by other members of the focus group (and walking group). The need to look out for each other while out walking together was evident across all the focus group data. At times, some participants walked slower than others which resulted in being left behind.

*Jamie: "Well we left her behind a few times"*



*Mairi: “Those two walk too fast for me. He’s [Lewis] not soo bad. I call him he gets gallus [overly confident] when we are out. I end up hunting for him, where is he now? Like the other day I shouted after him right Speedy Gonzales! It’s not a race!”*

*Lewis: “We call it power walking, that is more or less what he is doing...” (focus group 3).*

This shows the need for walk leaders who can monitor the group and ensure all members are safe, particularly when supporting individuals who have more severe to profound intellectual disabilities.

### ***Other drawbacks***

Other drawbacks associated with walking identified by a small number of people were a dislike or fear of dogs, the effort of making an early start in the morning, fatigue after walking and having to spend money on bus fares to meet their walking group at a particular location. In addition, while some individuals preferred to walk in a group, others commented on the diverse and sometimes conflicting needs of group members; for example an occasional 'disruptive' person or someone requiring one-to-one attention from the walk leader.

*Mairi: “When Gillian is near a road she has no road safety sense. So you really need to watch, I know the staff were doing it but the staff didn’t realise that she stopped to stay with me.” (Focus group 3).*

When talking to the participants in focus group 3, it was clear that they got on well together and looked after each other and other members of the walking group. Clearly social

relationships are an important part of people's lives; however, there are likely to be fewer opportunities for adults with intellectual disabilities to socialise in adulthood [27] which may also impact on opportunities to participate in physical activity or sport. This research suggests walking groups can provide an opportunity to meet and spend time with friends in an alternative environment to a day centre.

### **Theme 3: Walking choices**

#### ***Where to walk***

Some of the more independent walkers covered long distances, often as a means of purposeful travel. Tony used the route as a way to visit relatives.

*Tony: "I walked from my house all the way to [place name]."*

*Researcher: "Right okay, that is a long walk. How long did that take you?"*

*Tony: "About an hour and a half."*

*Researcher: "Did you walk back as well?"*

*Tony: "Yes."*

*Researcher: "...So why did you decide to walk there?"*

*Tony: "I was going to see my aunty and my cousin."*

Others had less choice and always walked with carers. Some larger day centres already had established walking groups that went out locally or drove to walking locations in a mini-bus.

A couple of the smaller centres set up groups as a result of the Walk Well programme. In Lindsay's day centre, staffing shortages meant the group taking part in the project usually walked round the inside of the centre. If someone was available to go with them, they walked round the outside of the centre. Thus, participants had limited choice about where to walk and when they could walk. Decisions were usually made by carers or more senior members of staff.

*Lindsay: "Some Wednesdays I would just walk round , in the centre, I would come out one door and go out that door and walk right round and come in the other door and I would do that about five or six times. Then one day Jackie said she was going to take us out a walk right round the centre outside and we done that about four, five or six times because they were a few of us." (interview 5)*

Participants with more independence who could go out alone often chose to walk in their local area, either going round the block a few times a day or every few days, or walking to a park or place of interest nearby. However, walking the same route became mundane for some and over time they began to lose motivation:

*Researcher: "Did any of your support workers ever go out walking with you?"*

*Aaron: "Yes at times, just your normal blocks and that."*

*Researcher: "Okay, so round the block. So how did you find doing that?"*

*Aaron: "A bit boring because it wasn't somewhere interesting. If it was somewhere like a museum..."(interview 1)*

### *Carers' role*

Although the walking advisor had suggested other routes Aaron could follow, he became disengaged with the programme over time and eventually chose to withdraw. When asked why he had initially decided to take part, it was clear the motivation had not come from him, but from a member of the staff at his provider organisation:

*Aaron: "They [staff] were kind of pestering me in a way."*

*Researcher: "Did you feel that you had the choice to take part or not?"*

*Aaron: "Yes and no, it was like being nagged at. So I said 'yes I will do it and try something new.'"*

Whilst some day centre/provider organisation staff encouraged participation in the walking programme, careful attention was paid to gaining participants' informed consent, throughout the duration of the study. However, previous research has suggested that people with intellectual disabilities may be more vulnerable and may feel obliged to take part in projects on offer to them, than other potential research participants (Iacono and Murray, 2003). Encouraging 'choice' about health is a contentious issue in this field and one that is complex. For example, in this study family carers also found ways to 'encourage' people to do more walking. Although weight loss was a key motivator for Heather, being offered a 'treat' (ice cream or sweets) and the promise of an I-pod from her sister Jane on completion of the project were also significant motivators:

*Heather: "...Because one time when I went round in circles and I went to the Admiral to get a Magnum [ice cream] there wasn't any, so I went out to the garage. It's a bit longer, an extra walk, to get a Magnum."*

*Researcher: "Okay."*

*Heather: "And I got [a] big double nougat." (interview7)*

Although effective in promoting short-term motivation, using extrinsic rewards such as food is seldom predictive of long-term behaviour change (Deci et al., 1999). Often, once the reward is removed, the behaviour diminishes. Other participants also talked about being offered food rewards by carers as a way to encourage walking:

*Warren: "Yes it [the shopping centre] is outdoors, but you don't get wet. We walked into it and then went to McDonalds and then back to the bus stop again...she [carer] said to me to go for a pizza." (interview 3)*

Using high-fat food and fizzy drinks as rewards for walking was also mentioned by carers who took part in the study (but were not interviewed formally). There seemed to be a consensus that this was an appropriate way to motivate people to engage in more physical activity. Previous research suggests that carers may have low knowledge about health recommendations (Melville et al., 2009). Given that some adults with intellectual disabilities rely heavily on carers' support, the carer's knowledge and behaviours may have a critical influence on individuals' lifestyle 'choices'.

#### **Theme 4: Using the Walk Well resources**

##### ***Walking plan***

Most participants reported adhering to the plan they had made with the walking advisor and felt setting goals and planning helped them walk more. However, Aaron felt restricted by it:

*Aaron: "I said I would plan to do it, - but it was more or less the thought of having to go when I said I would go. I didn't like being told.... maybe some of the people found it would be easier for them but for me I found it easier to do what I felt like."(interview 1)*

### ***The pedometer and walking diary***

There is strong evidence to suggest that self-monitoring our behaviour can support behaviour change (Bird et al., 2013, Lubans et al., 2009, Gleeson-Kreig, 2006). At the start of the programme, participants were given a pedometer, which recorded total number of steps per day, and were asked to wear it daily. At the physical activity consultations, the walking advisor showed participants and carers how to retrieve the daily step count, by pressing the top button on the device. To encourage self-monitoring, participants were also asked to record the count in a diary designed for this purpose.

Use of the pedometer and diary varied across participants. Most reported that they enjoyed wearing the pedometer and found it helped them to walk:

*Tony: "My mum had one and she always tried to compete with me."(interview 6)*

Overall, participants reported finding the pedometer easy to use, either on their own or with assistance from a carer/family member. Some remembered to wear the device daily without prompting whilst others needed more support. A few experienced problems putting it on and pressing the correct button.

However, understanding of the pedometer was varied. Some participants understood that the pedometer saved the weekly step count, allowing the user to retrieve 'missed' steps when filling in the walking diary. This resulted in some participants and/or carers filling in the

diaries weekly rather than daily. This may be less effective than daily monitoring and was not encouraged by the walking advisor.

*Warren: "You can go back to Saturday, Sunday or Monday and it saves you missing it out."*

*Researcher: "Okay so if you have forgotten to write your steps in it keeps them all."*

*Warren: "Yeah it puts them all in."(interview 3)*

Other participants knew that the pedometer recorded their steps, but were not sure what the number on the screen meant and whether it was close to 10,000 (the daily goal for the general population). Generally, those who did not have a family member or carer to help them struggled to write down their steps every day. Some participants forgot to record step counts, did not understand where or when to write them, or were unable to read and write the numbers:

*Claire: "I didn't actually write them down I just ticked them. I couldn't write them down. I just ticked the ones [days] that I did do."(interview 2)*

*Lindsay: "I was finding it hard because I wasn't sure what bit to write it."(interview 5)*

## **Discussion**

Overall, the participants interviewed generally had positive experiences of taking part in the Walk Well programme and a majority of participants reported physical, social and/or psychological benefits. In addition, there was often a sense of achievement in having

completed the programme. However, barriers to walking were identified, such as the weather a lack of available support from carers and drawbacks of walking with others.

This study shows that participants had different preferences regarding walking in a group with people they already knew, walking with one companion or walking alone. Therefore, **offering individuals a range of options may be an effective way to motivate people with intellectual disabilities to walk more.** In addition, some participants (not surprisingly perhaps) disliked walking 'round the block' or within a day centre. The walking advisor in the study encouraged and supported participants, carers and family members to plan walks and offered local maps of parks and green spaces. However, it appears the day centres did not have the staff capacity to go out, which may have resulted in more mundane walks.

Participants who were able to walk alone appeared to have more choice about where to walk, particularly if there were able to walk alone, however there appeared to be less 'choice' for those who required support or someone to walk with.

Critically, it appears walks were often arranged to fit in with the carers' plans or day centre schedule, suggesting that carers priorities and lifestyle behaviours can enable or thwart the lifestyle behaviours of individuals with intellectual disabilities, which is supported by previous research (Scott et al., 2014). **Future research should examine the carers' role, and how they influence choices about diet and activity, in order to enhance the effectiveness of future physical activity programmes with this population.**

This is the first study which has explored the use of self- monitoring to increase walking in adults with intellectual disabilities, therefore an important aspect of this study was to investigate if participants with intellectual disabilities can self- monitor behaviour. Whilst many of the participants were able to self- monitor their walking behaviour effectively, some



individuals appeared to have limited understanding of the pedometer and had difficulty with this technique. These individuals often struggled to understand the recorded step count and transfer it to their diaries. There is a strong evidence base for the effectiveness of self-monitoring as a technique to encourage change in PA or diet behaviour in the general population (Gleeson-Kreig, 2006, Bird et al., 2013, Lubans et al., 2009). The results from this study suggest that generic behaviour change techniques (such as self-monitoring behaviour with a pedometer) may not be the most appropriate approach. While previous research with adults with intellectual disabilities have focussed on changing the behaviour of carers (Bergstrom et al., 2013, McDermott et al., 2012), we believe working with the individual promotes choice and personal agency. We acknowledge there may be challenges supporting some people with intellectual disabilities to change behaviour using such techniques, therefore one suggestion is to develop new smart technology for this population, which records steps but provides visual rather than numeric feedback on progress. Walking advisors or carers could assist with reviewing and, where appropriate, revising goals with participants.

**Future research to examine the effectiveness of different technologies that support self-monitoring would be beneficial in improving the health and well-being of this population.**

Finally, the results identified some risks from walking, for individuals with intellectual disabilities. The walking advisor's role was to encourage walking and other physical activities with a psychological based physical activity consultation, therefore it was made clear to the participants, carers and parents that they should make the decisions about who and if an individual would require support when walking (as they were better placed to assess the participants' capabilities and possible challenges that may be encountered). (Manthorpe, 2000).

This qualitative study included a sub sample of adults with intellectual disabilities, who had participated in a large scale RCT intervention tailored to their needs. While this approach was appropriate for working with individuals with varying levels of intellectual disability and support needs, the researchers acknowledge that the experiences presented in this paper represent a very small and specific population group.

This is the first qualitative study which has explored adults with intellectual disabilities experiences of taking part in a community based walking programme, therefore we begin to add to the scant literature base which is capturing the views of those with intellectual disabilities. Exploring participants' experiences of taking part in walking programme offers valuable insights as to why an intervention may or may not be effective in changing behaviour. This is crucial for advancing the effectiveness of future interventions, helping them to improve the health and well-being of all populations. Research which provides individuals with intellectual disabilities with a voice is scarce (Scott et al., 2014) but vital if we are to work to reduce the health inequalities of this population. It is hoped that this research may create opportunities for discussion that may illuminate, challenge and disrupt theories and understandings of why individuals with intellectual disabilities may be less active, have poorer health and wellbeing and how these physical activity experiences exist in different contexts, can be overcome, addressed or at least acknowledged.

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### **Declaration of interest**

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