

Barriers to increasing the physical activity of people with intellectual disabilities: A qualitative study

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Accessible summary

- **We talked to people with intellectual disabilities and their carers about being healthy**
- **Sometimes it was difficult for people with intellectual disabilities to take part in activities that would help keep them healthy**
- **Being active is not just about doing special sports and activities. It can be part of everyday life**
- **People with intellectual disabilities could become more active and be healthier with help from their carers**

Abstract

Background: The prevalence of obesity, inactivity, and related morbidity and mortality is higher amongst people with intellectual disabilities than in the population in general; an issue of global concern. This research examined the perspectives of people with intellectual disabilities and their carers, on exercise and activity.

Materials and Methods: Qualitative data were collected via interviews and a focus group with people with intellectual disabilities and their paid and family carers, recruited via state funded community based day centres in Scotland.

Results: Three barriers hindered service users with intellectual disabilities from regular involvement in physical activity: (1) Acceptance of an inactive lifestyle by carers; (2) Restrictions on activity due to paid carer preferences and resource limitations; (3) Communication issues between family carers and paid carers. Barriers were based on assumptions made by paid and family carers, so there is potential to increase activity by changing attitudes, improving communication and

reconceptualising activity as integral to everyday living, rather than as additional exercise requiring special resources.

Conclusions: Carers should be supported to promote physical activity in a variety of ways to enhance the motivation of service users, to encourage them to engage with physical activity as an integral part of a healthy life style, and to transfer this to their lives beyond day care.

Key words

barriers, choice, motivation, responsabilisation

Background

Physical activity is important for people's health and well-being and this applies to people with intellectual disabilities, for whom there is increasing concern about obesity and its impact on health (Bhaumik et al., 2008; Melville et al., 2006; Finlayson et al., 2009; Hilgenkamp et al., 2012). Obesity prevalence is possibly 59% higher than in the general population, and obesity related health conditions, including increased cholesterol levels, type 2 diabetes, cancers and cardiovascular disease (Haidar and Cosman, 2011), appear to develop earlier in people with intellectual disabilities than in the general population, possibly due to higher obesity prevalence (Doody and Doody, 2012), increasing premature mortality (Scottish Executive, 2004).

Low levels of physical activity in people with intellectual disabilities appear to be an issue of global concern; in the UK, people with intellectual disabilities are 'significantly more likely to lead sedentary lifestyles' (Emerson, 2005: 135), which may partially account for the high prevalence of obesity. In a recent moderately large USA sample most participants were overweight or obese and physical activity levels were below national averages (Barnes et al., 2013). A study of 68 adults with intellectual disability in Australia 'indicated that the majority of participants (60.3%) did not meet national physical activity guidelines' (Koritsas and Iacono 2016: 355). Low levels of physical activity in people with intellectual disability appear to be common across the lifespan, a Swedish study by Sundahl et al (2016) notes that low levels of physical activity are common in young adolescents and adults with intellectual disability, especially women. At the opposite end of the life-span, studies by Hilgenkamp et al (2011) in Holland and Dixon-Ibarra et al. (2013) in the USA report low levels of physical activity in older adults.

Increasing activity levels amongst people with intellectual disabilities increases their physical, and cognitive capabilities, their well-being, and their social engagement (Bartlo and Klein, 2011; Hutzler and Korsensky, 2010; Johnson, 2009; Li et al., 2013; Shin and Park, 2012). Overall:

Increasing levels of moderate or vigorous physical activity among people with intellectual disabilities would be the single most effective way of improving the health of people with intellectual disabilities (Robertson et al., 2000: 469).

Current Scottish recommendations are for adults to engage in 150 minutes of moderate or 75 minutes of vigorous physical activity per week (Department of Health, 2011; Scottish Government, 2014). A Scottish Health Survey carried out in 2013 indicated that 64% of adults now achieved this recommendation, which is an increase on previous years (Scottish Government, 2014: 160). Attitudes to physical activity were reported as being 'very positive' when the then Scottish Executive carried out a survey in 2006 (Murray, 2006: 2) and this positive attitude was also noted in a study based on Glasgow residents (Glasgow Centre for Population Health, 2011). There is relatively little comparable data for information regarding physical activity levels of adults with an intellectual disability in Scotland. Finlayson et al. (2009: 244) reported that in a sample of 433 adults with an intellectual disability only 5% met the Government recommendations for physical activity. Finlayson et al. (2011: 508) also found in a study investigating measurement of physical activity involving a sample of 62 adults with mild to moderate intellectual disability only 6 (15%) met Government recommendations.

Setting

The research took place in day centres in East Lothian and Midlothian, Scotland, which comprise parts of the suburbs and rural hinterlands of Edinburgh. A research assistant, who was a PhD qualified medical sociologist, initially contacted the centre project leaders, then with their agreement (which was never denied) ran information sessions for service users with their paid carers also present, to provide advance information and begin the process of informed consent. The research assistant also discussed with project leaders which service users might be suitable participants and whose family carers might also be willing to participate. All services are state funded and anyone wishing to use them is eligible even without an official diagnosis of intellectual disability.

Ethics and consent

The ethics committee of Queen Margaret University approved this research, which conforms to the Declaration of Helsinki. As one of the stakeholder groups, the service users with intellectual disabilities, involved in this study was particularly vulnerable it was essential to have robust procedures to ensure fully informed consent was obtained from all participants. The recommendations made by Cameron and Murphy (2006) were used. All written materials for participants were edited to have a Fleisch-Kincaid reading Grade of 4.7, in order to be appropriate for people with intellectual disabilities. Potential participants with intellectual disabilities and their carers or paid carers were given information explaining the nature and scope of the research sufficiently in advance of the interviews to allow them to reflect on and consider participation. There was an initial session where the researcher verbally explained the research and potential participants could ask questions. Next, background information was provided in what Cameron and Murphy (2006: 114) describe as an 'illustrated

summary letter.' After reflection and discussion, by signing the summary letter the participants provided their consent to participation. Prior to interview (or focus group) continued consent was checked verbally. Throughout the interviews, the researcher observed nonverbal cues and monitored the communication between participants with intellectual disabilities and any carer present, to ascertain whether the participant with intellectual disabilities continued to consent (which was re-checked verbally periodically), to identify any leading or suggestion that may have been taking place, and to reduce the participant providing responses to questions that may have been given to please the carer rather than representing their reality. The other stakeholder groups signed more traditional consent forms.

Participants

The 42 participants included: 12 project leaders; 10 family carers; 10 paid carers and 10 service users with intellectual disabilities (5 male, 5 female by design). The service users with intellectual disabilities were all over the age of 18 and had been classified as obese by medical professionals. The paid carers worked in the day centres the service users attended. Project leaders were responsible for managing the service and were accountable for the delivery of care. Family carers were all parents of service users. Data were collected through state funded community based day centres in Scotland. More detailed participant information has not been included here to maintain confidentiality, as the pool of available participants in the geographic area is small.

Aims

The research sought to gain an understanding of the causes of obesity from the perspectives of people with intellectual disabilities and their carers.

Research Questions

1. What are obese people with intellectual disabilities' and carers' perspectives on activity both for themselves and each other?
2. How do obese people with intellectual disabilities and their carers communicate and negotiate activity?
3. How do the attitudes and interactions in questions 1 and 2 affect activity levels?

Method

A qualitative research design was used to enable a detailed investigation of the experiences of the participant groups. Each participant group was interviewed with data being collected through one to one semi-structured interviews. Table 1 below details the topic schedule used for each participant group. Grounded theory methods were used and this initial topic schedule was used as a framework that could be adapted as grounded theory is underpinned by the constant comparative approach to data collection and analysis (Charmaz, 2014). Data that were collected from the service users was strengthened by the addition of a focus group meeting to enrich the representation of their perception of their own lived reality (Mason, 2002). Five of the service users were involved in this activity.

During coding and analysis, the research team identified groups of codes that emerged from the data. These groups were then organised into categories (Saldana, 2011). By examining these categories a number of themes were identified. It was at this stage in the analysis that memos were used as a device to support the interpretations that were made from the data and to make the analysis more abstract (Mason, 2002). By adopting a team approach to data analysis, the interpretations of

the data were cross checked enabling the research team to be confident the analysis reflected the codes, categories and themes identified in the data. This paper is based upon the themes that emerged during the analysis about physical activity.

Results

The results reported here focus on the barriers that prevented the service users engaging in meaningful regular physical activity, which were in part constructed by the actors responsible for caring for the service users.

Both paid carers and family carers in this study identified a lack of physical activity as being a contributory factor in the service users that they cared for having weight problems. The family carers made statements such as:

She was more active when she was at school (family carer 4).

But it's definitely not what she eats...because I mean she is just sitting around all night not doing anything (family carer 8).

Many of the paid carers also articulated the opinion that insufficient activity was the main issue that led to weight problems in this service user group:

I think he could be much more active and if he could lose a bit of weight (paid carer 1).

A number of the project leaders also articulated the view that it was a lack of physical activity that was a contributory factor in causing the obesity that the service users with intellectual disabilities experienced. So both carer groups and project leaders agreed that inactivity was an issue.

Barriers

Three types of barrier were found in the data; acceptance of an inactive lifestyle by those responsible for providing care; paid carer preferences coupled with resource limitations; finally communication issues between family carers and paid carers.

Inactive lifestyle

The first barrier was acceptance by the family carers that it was difficult to encourage the service users to be physically active:

She does have a treadmill in her bedroom that she never goes on. We try to encourage her but when she comes in its sitting down watching telly (family carer 4).

Adjunct to this assumption was the feeling that service users were content to be inactive:

[T]he staff would say do you want to go swimming or do you want, no I can't be bothered. She would rather sit and play with her phone or play her music (paid carer, 4).

Family carers also described that they did not engage in physical activity themselves:

Well I used to take her a lovely walk and that but I'm not able to now (family carer 7).

Family carers were predominantly the parents of adult children, and it is likely that they had both actual and perceived age-related physical limitations. This not only limited their own physical activity, but also their children's because many of the service users required supervision and support to engage in physical activity:

So her mum likes her to be in this very safe environment and for example, she was to get to the hydro-pool. But mum only wanted particular staff to go with her (paid carer 6).

Combined, these issues created a social situation where the service users were not sufficiently encouraged to participate in physical activity. They may also have been

modeling the behaviours and attitudes of their family carers. Evidence of this behaviour modeling was identified in 6 of the service user interviews with this group describing physical activity as hard work rather than as fun or something enjoyable.

Furthermore, the paid carers suggested that family carers were more comfortable when the service users were being supervised and only engaging in activities that were safe (as highlighted in the quotation above), and family carers also suggested they were no longer able to supervise or lead physical activities themselves.

Family carers tended to regard the issue of low physical activity as one that should be redressed in the form of an organised intervention arranged by professional carers. The family carers directed responsibility to paid carers and services both for encouraging service users to be involved in physical activity and for arranging any such activities. Many of the family carers outlined a range of organised events that the service users took part in, which were arranged by the day centres and paid carers:

She does Zumba at her centre one afternoon a week and she is away swimming this morning apart from that that's it (family carer 4).

However, the family carers also described how these programmes had been cancelled:

I know she went to some dancing things as well, she liked that, but it was stopped (family carer 9).

Service users also reported this:

Cos I haven't been out much, cos its been cancelled swimming here (service user 10).

There appeared to be a lack of desire or ability to seek out physical activity independently of the day centre. Furthermore, the family carers appeared to place responsibility for this part of a healthy life style onto actors outside the family:

There's not much I could do about it. I often hope that they really take something up in the centre (family carer 6).

There are two strands then to the acceptance barrier: First, the acceptance of an inactive lifestyle; Second that the responsibility for arranging physical activity was with the paid carers. Rather than motivating the service users to participate in activities away from the home, for example, in democratic open spaces such as parks or in public leisure facilities such as sports centres the family carers appeared to be placing responsibility for this aspect of the caring task with others. There is also an implicit conceptualization of 'physical activity' as something that involves organised activities that are different from usual and are not particularly desirable in their own right.

Resource limitations

The cancellation of activities and the responsabilisation of the paid carers by the family carers outlined above are connected to the second barrier to the service users being more physically active. This related to staffing levels and staff preferences in the day centres. The following quotation from a paid carer illustrates the difficulties relating to staffing levels:

But right now group's not on because when there's holiday the group doesn't happen (paid carer 2).

Furthermore, the concern articulated by the family carers about activities being cancelled (that were described earlier in this paper) as a consequence of a perceived lack of staff was also supported by data gathered during the focus group meeting that the service users with intellectual disabilities attended:

SU: I used to do that all the time. I used to be on a wee horse but it stopped.

Researcher: Did you? On the horses? So, some things that you can do through the centre and sometimes you can't do them because the centre's not running them?

SU: When they're not short of staff [*laughter*].

SU: If the manager turns up.

The amusement demonstrated by the service user here is perhaps an indication that being short of staff is something that the service users experience frequently. This interpretation of the data is supported by comments made by both family carers and paid carers. This barrier is especially interesting as both the family carers and paid carers identified a lack of physical activity as being a key driver of weight gain in the service users, yet it appeared to be common practice to cancel activities after resources had been used arranging it. This appears counterproductive in two ways. First, it may be interpreted by service users to mean that physical activity is less important than other activities that are less staff intensive. Secondly, using resources to plan activities that are then not followed through is wasteful of limited staffing resources. The number of staff required to support an individual engage in an activity depends on that individual's needs and abilities but for some individuals doing an activity could require two or more members of staff.

However, the project leaders described how programmes were developed to account for the changing staffing arrangements in the day centres:

We have fewer staff than we would need to make sure everybody had all those needs met all the time, that we have a compromise and people have their needs met part of the time. We simply are not equipped to manage to do that all the time. And to some extent that's ok, because you can't occupy people all the time (project leader 6).

The project leaders linked funding to the ability to offer regular physical activities and the frequent cancellation of this type of intervention (that was reported by the family

carers and service users) perhaps reflects the difficulties the project leaders faced managing their budgets especially as the provision of physical activity did not form an explicit part of the funding the project leaders received. This may also help account for the limited opportunities that service users with intellectual disabilities have for recreational activities, including physical activity.

Paid Carer Preference

The other strand to the second barrier to physical activity being examined in this paper is paid carer preference. The paid carers described how the activities on offer at the day centre were in part designed to suit the needs of the centre rather than the needs of the service user:

So it's what suits the staff a hundred per cent I don't think that it's fully service user orientated which they say it is (paid carer 6).

A lack of guidelines may also have influenced the final barrier that is a lack of communication between the family carers and the paid carers, which created a situation where each of the carer groups responsabilised the other for making sure that the service users with intellectual disabilities were engaging in sufficient physical activity to promote their long-term good health. Both family carers and paid carers described a system of annual reviews when each service user's needs were discussed and plans were agreed for the year ahead:

...about once a year ...[w]e have what is called a PCP which is just a review of how things are going and obviously social workers have to get involved, parents, any other interested parties are invited along to that (paid carer 1).

These reviews were used to agree which activities the service user should attend, but did not set goals or expectations regarding the amount of physical activity that should

be attained, or discuss how to motivate service users. This allowed both paid and family carers to diffuse responsibility for physical activity and direct it to the other group.

The ways in which the family carers responsibilised the paid carers for arranging physical activities for the service users was described above. The paid carers in turn directed responsibility for the lack of activity back to the family carers by highlighting what they perceived to be a lack of support for physical activity:

[There is] very little interest in doing exercise and you've got no support from mum (paid carer 6).

On the other hand, family carers suggested that it was the responsibility of the paid carers to support the service users to become active and become involved in physical activity:

There's not much I could do about it. I often hope that they really take something up in the centre (family carer 6).

There was an awareness shown amongst both the carer groups that physical activity was a key component in a healthy life style and that physical activity was needed to support a healthy weight; however, paid carers frequently suggested that encouraging activity was a family responsibility, and blamed family carers for inactivity. This caused a degree of tension:

But we cannot control what happens when he leaves here and I think the big issue is there rather than here (paid carer 1).

However, the family carers whilst suggesting it was the responsibility of the paid carers to arrange physical activities, were less critical when describing the paid carers perceived failing in this area. Service users' physical activity was caught in a gap

between the paid carers and family carers with neither group leading on promoting and facilitating physical activity. In this context service users were able to default from more strenuous activity in favour of what the paid carers described as 'groups' that consisted of craft based activity or cooking. Furthermore, the barriers described in this paper were compounded by the sedentary lifestyle that many day centres appeared to accept as being normal:

Whereas in the community people tend to sit in front of televisions quite a lot, I have to say. Now that is their choice and I can't dictate otherwise. And they tend to have transport to take them to the shops rather than just walk. I do think that there is a difference in some cases and again as we talked about earlier that depends on the staff too (project leader 8).

Communication

This leads on to the final aspect of the communication gap barrier, which was having low aspirations for physical activity amongst service users, and not prioritising increasing their activity levels, which included making assumptions that their current low levels of ability was all of which they were capable:

So the whole drive and programme to promoting people's wellbeing encourage us to look at activities that meet people's needs and encourage a positive approach to healthy lifestyles, but that would depend on the abilities of the individuals, and the levels of support that are available. So services aren't resourced to really make that happen, but they're encouraged through the standards that we're expected to work to (project leader 7).

The service users with intellectual disabilities were in many cases framed as lacking ability to be involved in physical activity. Understanding service users as lacking the capability to engage in activities enabled the paid carers to deliver care in ways which suited the service rather than meeting the needs of the service user, from the rationalisation that it was necessary to accept that they (and their families) were inactive.

Discussion

Previous research clearly documents that this service user group tend to be even less active than the general population (Emerson, 2005; Finlayson et al., 2009). A recent systematic review highlighted the need for research that considers the barriers that may prevent service users with intellectual disabilities taking part in regular physical activity (Harris et al., 2015). This study offers a preliminary understanding of three barriers that hindered increasing activity levels: (1) Acceptance of current levels of inactivity; (2) rendering physical activity a low priority compared to other activities both in timetabling and in resource allocation; (3) issues regarding communication and the appropriate format for physical activity.

Acceptance of an inactive lifestyle

Acceptance of inactivity tended to be expressed in terms of the assumed preferences of others. Paid carers felt that service users and family carers preferred sedentary activities. Service users and family members felt that paid carers were not always able to staff physical activities adequately so cancelled them. In terms of prioritizing physical activity, stakeholders often justified their low priority in terms of having tried such activities and/or provided the equipment and resources, but that this had not worked out due to resource limitations or family preferences. However, shorter, more regular activities may be more beneficial than longer, more elaborate ones (Shin and Park, 2012). This may also help embed sustainable change into everyday life (Lante et al., 2014).

Carer preferences and communication

Preferences and priorities did not appear to be commonly discussed, despite the acknowledged importance of physical activity for health. This communication gap included role ambiguity between family and paid carers, with both groups believing that the other group should have primary responsibility for increasing service users' activity levels. Unclear policy guidelines may contribute to this barrier (Messent et al., 2009) and clear direction from project leaders may support improvements in this aspect of service provision.

The main way of achieving more physical activity was thought to be specific activities that should be 'added on' to everyday life (where sedentary activities were assumed the norm), such as swimming, horse riding, or using a treadmill. These assumptions are no different from normative assumptions made by the general population. Current advice is that weight management is best achieved with a sustained programme of lifestyle change (Scottish Government, 2013). For service users, this would involve centering physical activity in their lives, rather than adding it on. This would require communicating about actual preferences, as well as safety and resource issues. Many homes contain unused exercise equipment because it does not suit the activity needs of the occupants. Many people struggle to incorporate exercise into their weekly routines. So the relative inactivity of service users does not necessarily suggest a preference for sedentary activities but rather a lack of feasible physical activities.

Family carers were predominantly older adults caring for their adult offspring, so they did not feel able to take the lead on promoting physical activity in the family. Nor did it help that the service users were obese, for obesity limits people's physical abilities

(Murray, 2006; Finlayson et al., 2009; Harris et al., 2015). The view of physical activity as a special task that required special arrangements mirrors other findings that participants considered a healthy diet to involve going on a diet which necessitated eating special foods and avoiding other foods (Cartwright et al., 2014). The similarity lies in thinking about health as involving additional activities that can be resource intensive and less intrinsically desirable than normal activities, rather than being integral to everyday life and beneficial for everyday wellbeing. Instead of accepting this situation, professional carers need to take up the responsibility for increasing service users' physical activity levels.

Conceptualising physical activity as an add-on unwittingly raised barriers because special activities, especially outside the day centre, can be resource intensive and logistically complex. There needs to be creativity and ingenuity in developing ways of increasing physical activity within the normal routines of day care.

Ideally, day centres need to develop policies to increase activity levels, by integrating sociable physical activities into everyday routines, by explicitly rejecting the acceptance and facilitation of inactivity, and by being willing to show service users how to do activities (Temple, 2009). For example, electronic games consoles include many games that involve physical activity and are sociable. Such activities can be less staff intensive, can occur within the normal routine of the day centre, are an alternative form of social interaction to the 'groups' that the paid carers described as consisted of cooking based activity, and can be incorporated into annual plans. Social activity has been found to be 'an important predictor of BMI scores in people with intellectual

disability' (Doody and Doody, 2012: 465). Including physical activity that has a social aspect could help address the problem of modeling the behaviours and attitudes of family carers described earlier in this paper.

Conclusion

This paper identifies barriers that could be addressed by organisational change with the aim of giving greater priority to the need for physical activity in the lives of people with intellectual disabilities. It is suggested that given its importance for health, local authorities that provide day services and fund service provider organisations, should consider including the need to engage in physical activity in job descriptions for project leaders and paid carers. Similarly local authority run services and care provider organisations should be encouraged to consider it an integral aspect of their organisation's ethos and philosophy. By incorporating this policy into job descriptions, practice within this type of setting could be improved.

Whilst it may be difficult to achieve government targets regarding physical activity, support plans could include opportunities for developing and promoting physical activities based on the needs and abilities of individual service-users. Service users must be included in the design and planning of any changes as it is important to include their voice in a meaningful way. By making sure they are at the centre of the process, any life style changes are more likely to be sustained. By working in partnership with service users; project leaders, paid carers and family carers may be able to encourage service users to engage in physical activity that is fun and something to look forward to, thereby making it a part of everyday routine and a positive lifestyle choice.

Whilst this research has some limitations (the relatively small sample size and small geographic recruitment area) it has highlighted a need for further research specifically designed to explore the barriers identified in this paper.

References

Barnes, T.L., Howie, E.K., McDermott, S. and Mann, J.R. (2013) Physical Activity in a Large Sample of Adults With Intellectual Disabilities. *Journal of Physical Activity & Health* **10(7): 1048-1056.**

Bartlo, P. and Klein, P.J. (2011) Physical Activity Benefits and Needs in Adults With Intellectual Disabilities: Systematic Review of the Literature. *Ajidd-American Journal on Intellectual and Developmental Disabilities* **116(3): 220-232.**

Bhaumik, S., Watson, J. M., Thorp, C.F., Tyrer, F. and McGrother, C. W. (2008) 'Body mass index in adults with intellectual disability: distribution, association and service implications: a population-based prevalence study', *Journal of Intellectual Disability Research*, **53, 287 – 298.**

Cameron, L. and Murphy, J. (2006) 'Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities' in *British Journal of Learning Disabilities*, **35, 113 – 120.**

Cartwright, L., Reid, M., Hammersley, R., Blackburn, C. and Glover L. (2014) 'Food choice by people with intellectual disabilities at day centres: A qualitative study' in *Journal of Intellectual Disabilities*, **1 - 13** DOI: 10.177/1744629514563423.

Charmaz, K. (2014) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, 2nd edition, London: Sage Publications.

Department of Health (2011) Physical activity guidelines, London: HMSO.

Dixon-Ibarra, A., Lee, M. and Dugala, A. (2013) 'Physical activity and sedentary behavior in older adults with intellectual disabilities: a comparative study' in *Adaptive Physical Activity Quarterly* **30(1), 1 – 19.**

Doody, C. M., and Doody, O. (2012). 'Health promotion for people with intellectual disability and obesity' in *British Journal of Nursing*, **21 (8), 460 - 465.**

Emerson, E. (2005) 'Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England' in *Journal of Intellectual Disability Research*, **49 (2), 134 – 143.**

Finlayson, J., Jackson, A., Cooper, S-A., Morrison, J., Melville, C., Smiley, E., Allan, L. and Mantry, D. (2009) 'Understanding Predictors of Low Physical Activity in Adults with Intellectual Disabilities' in *Journal of Applied Research in Intellectual Disabilities* **22, (3), 236 - 247**

Finlayson, J., Turner, A. and Grant, M.H. (2011) 'Measuring the actual levels and patterns of physical activity/inactivity of adults with intellectual disabilities' in *Journal of Applied Research in Intellectual Disabilities*, **24, (6), 508 - 517.**

Glasgow Centre for Population Health (2011) *Public attitudes to Physical Activity in Glasgow*, Glasgow: EKOS Ltd.

Haidar, Y. and Cosman, B. (2011) 'Obesity Epidemiology' *Clinics in colon and rectal surgery*, **24 (4)**, 205 – 210.

Harris, I., Hankey, H., Murray, H. and Melville, C. (2015) 'The effects of physical activity interventions on preventing weight gain and the effects on body composition in young adults with intellectual disabilities: systematic review and meta-analysis of randomized controlled trails' in *Clinical Obesity* **5**, 198 - 210

Hilgenkamp, T., Reis, D., van Wijck, R., and Evenhuis, H. M. (2011) 'Physical Activity levels in older adults with intellectual disabilities are extremely low' in *Research in Developmental Disabilities* **33, (2)**, 477 - 483.

Hilgenkamp, T., Reis, D., van Wijck, R., and Evenhuis, H. M. (2012) 'Low physical fitness levels in older adults with ID: Results of the HA-ID Study' in *Research in Developmental Disabilities* **33, (4)**, 1048 – 1058.

Hutzler, Y. and Korsensky, O. (2010) Motivational correlates of physical activity in persons with an intellectual disability: a systematic literature review. *Journal of Intellectual Disability Research* **54**: 767-786.

Johnson, C.C. (2009) The Benefits of Physical Activity for Youth With Developmental Disabilities: A Systematic Review. *American Journal of Health Promotion* **23(3)**: 157-167.

Koritsas, S. and Iacono, T. (2016) 'Weight, nutrition, food choice and physical activity in adults with intellectual disability' in *Journal of Intellectual Disability Research*. **2 (60)**, 355-364.

Li C., Chen S., How, Y.M. and Zhang, A.L. (2013) Benefits of physical exercise intervention on fitness of individuals with Down syndrome: a systematic review of randomized-controlled trials. *International Journal of Rehabilitation Research* **36(3)**: 187-195.

Mason, J. (2002) *Qualitative Research*, London: Sage Publications.

Melville, C. A., Hamilton, S., Hankey, C. R., Miller, S. and Boyle, S. (2006) 'The prevalence and determinants of obesity in adults with intellectual disabilities' in *Obesity review*, **8**, 223 – 230.

Messent, P., Cooke, C. and Long, J. (2009) 'What Choice: A Consideration of the Level of Opportunity for People with Mild and Moderate Learning Disabilities to Lead a Physically Active Healthy Lifestyle' in *British Journal of Learning Disabilities*, **27 (2)**, 73 – 77.

Murray, L. (2006) *Sport, Exercise and Physical Activity: Public Participation, Barriers and Attitudes*, Edinburgh: Scottish Executive.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Turner, S., Kessissoglou, S. and Hallam, A. (2000) 'Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities' in *Research in Developmental Disabilities*, **21**, (6), 469 – 486.

Saldana, J. (2011) *The Coding Manual for Qualitative Researchers*, London: Sage Publications.

Scottish Executive (2004) *Improving the Health and Wellbeing of People with Learning Disability and/or Autistic Spectrum Disorder* at <http://www.chp.scot.nhs.uk/wp-content/uploads/Improving-the-Health-of-People-with-Learning-Disability-and-or-Autistic-Spectrum-Disorder.pdf> (accessed 9th May 2013).

Scottish Government (2013) *The Keys to life: Improving quality of life for people with learning disabilities*, Edinburgh: The Scottish Government.

Scottish Government (2014) *Scottish Health Survey*, Edinburgh: The Scottish Government.

Shin, I-S. and Park, E-Y. (2012) 'Meta Analysis of the effect of exercise programs for individuals with intellectual disabilities' in *Research in Developmental Disabilities* **33**, (6) 1937- 1947.

Sundahl, L., Zetterberg, M., Wester, A., Rehn, B. and Blomqvist, S. (2016) 'Physical Activity levels among adolescents and young adult women and men with or without intellectual disability' in *Journal of Applied Research in Intellectual Disabilities*, (29), 93-98

Temple, V.A. (2009). Factors associated with high levels of physical activity among adults with intellectual disability. *International Journal of Rehabilitation Research*, **32**, 89-92. doi: 10.1097/MRR.0b013e328307f5a0

Table 1. Topic Schedule

Questions for service users

- Q. What is your favorite sport or exercise?
- Q. How often do you do this?
- Q. How important do you think it is to be fit and healthy?
- Q. Does [paid carer] do exercise with you?
- Q. Who chooses what exercise you do?
- Q. Can you think of ways that you could improve your exercise?
- Q. Is there anything that stops you from doing exercise?

Questions for both carer groups (family carers and paid carers)

- Q. What exercise does [name] take part in?
- Q. What is your role in encouraging [name] to be active or exercise?
- Q. How important do you think it is to be fit and healthy?
- Q. What might the consequences of not doing enough exercise be?
- Q. How much does [name] have a choice in physical activity?
- Q. What do you think would help in ensuring [name] takes appropriate exercise?
- Q. Is there anything that you think may stop [name] from being able to exercise?

Questions for project leaders

- Q. What exercise or activity do clients take part in?
- Q. How important do you think it is to be fit and healthy?
- Q. What might the consequences of not doing enough exercise be?
- Q. How much do clients have a choice in physical activity?