

Enabling older adults with intellectual disability to become physical activity leaders in their community: Pilot study

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Journal of Intellectual Disabilities
2023, Vol. 0(0) 1–17

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DOI: 10.1177/17446295231177190

journals.sagepub.com/home/jid



Abstract

People with intellectual disabilities (ID) have high levels of sedentary behaviour and co-morbid health conditions. There is also increased longevity for this group which is an incredible success story but one which also poses challenges to the health system. For the first time, the mainstream health system needs to plan for and address age related health needs of people with ID. It also demands consideration of age-appropriate health-promotion efforts to support this ageing population with life-long disability. A physical activity programme, People with Intellectual Disability as Physical Activity Leaders (PPALs), was co-designed and co-developed with older adults (40+ years) with intellectual disability (ID). The process, content and outcomes of the pilot are presented in this paper. Expertise from three sectors: non-statutory academic and people with intellectual disabilities and their supporters worked collaboratively for successful completion of the project.

Keywords

physical activity, intellectual disability, older adults, peer leadership, enable

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Introduction

It is widely reported that there are increased levels of sedentary behaviour within our societies today (Hilgenkamp et al., 2012a; Lynch et al., 2021) which has implications for individual health outcomes as well as pressures on the health system. There is a need to focus on lifetime promotion of physical activity in this specific population. People with intellectual disabilities (ID) are no exception to the impact of low physical activity on health and are a rapidly growing population. In fact, research shows that people with intellectual disabilities are at greater risk of low levels of physical activity, have less opportunity to engage in physical activity (Emerson, 2005) and as noted in the general literature on this topic this appears to contribute to high levels of comorbidity including obesity (Waninge et al., 2013). Specific physical activity training programmes for the older population of people with intellectual disability are lacking. In addition, there is a dearth of examples of people with intellectual disability taking leadership roles in training programmes.

A more recent phenomenon, is that people with an intellectual disabilities are experienced increased longevity (Kelly and Kelly, 2011). Ageing is a great success story, resulting in an older population of people with intellectual disability for the first time (Hilgenkamp et al., 2012a). This longevity is comparable to the general population except for people with more severe intellectual disabilities. In the 2016 Census in Ireland, there was 66,611 people living with an intellectual disability in Ireland, which represented an increase of 15.4% (n=8902) since the last census in 2011 (CSO, 2016).

However, increased life expectancy also demands effective planning for and addressing of ageing related health needs of this population through mainstream health services. It also demands consideration of age-appropriate health-promotion efforts to support this ageing population with life-long disability.

The physical activity pilot programme described in this paper aims to draw together expertise from three sectors: a non-statutory agency (with focus on ageing and physical activity in the general older population), the academic research sector in Ireland and Spain (with a focus on the health and ageing experience of people with intellectual disabilities) and people with disabilities and their support workers.

This study set out to address two goals:

1. To increase opportunities for inclusion for people with ID in physical activity and citizen engagement through physical activity.
2. To develop a leadership programme for older people with intellectual disability through the mechanism of physical activity programming.

The paper presents findings from a pilot development and delivery of the physical activity leadership intervention with older people with intellectual disabilities in Ireland. The People with Intellectual Disability as Physical Activity Leaders (PPALs) programme was co-designed and co-developed with people with ID aged 40 years and over. People with intellectual disabilities attended a six-week training programme in Trinity College Dublin. In parallel, with the training programme in Ireland, partners in the University of Barcelona, translated the training materials and piloted the programme with people with intellectual disability in Spain. The current paper reports on the results of the Irish study only.

Physical Activity (PA)

Physical activity (PA) is defined as any bodily movement produced by skeletal muscles that requires energy expenditure (WHO, 2018). Physical activity can be seen in the light of prevention of diseases, disease control, and maintenance of physical and psychological health (ACSM, 2014, WHO, 2018). In today's world, PA plays a vital role in the health and wellbeing of everyone. Physical Activity also plays a critical role in the prevention of secondary health conditions. PA benefits overall health by reducing morbidity and mortality (Warburton et al., 2006). In order to maintain a healthy lifestyle, it is recommended 30 minutes of moderate to vigorous activity is undertaken for five or more days a week (WHO, 2018). In contrast, sedentary behaviour (lack of physical activity) has been identified as the fourth leading risk factor for global mortality (6% of deaths) globally.

Many studies and programmes show great improvements to people's health and wellbeing due to the introduction of health promotion interventions, particularly those targeting increased physical activity. Benefits in other areas of life such as building an individual's confidence, motivation and offering leadership roles within their community have been shown to materialise. For people with intellectual disabilities. The importance and benefits of health promotion and physical activity are just as important for people with intellectual disabilities as it is for the general population (Dairo et al., 2016).

People with intellectual disabilities have multifaceted health conditions and higher levels of multi-morbidity (McCarron et al., 2013). Being overweight and obese have been highlighted as a major determinant of chronic ill health as individuals age (Melville et al., 2007) and the extant research evidence illustrates that adults with intellectual disability experience even greater health risks compared to the general population, with regard to overweight and obesity (Wanninge et al., 2013), physical inactivity (Hilgenkamp et al., 2012c, 2012b) and high levels of sedentary behaviour (Melville et al., 2017). Such unhealthy behaviours lead to increased risk of early mortality (Melville et al., 2007) diminished quality of life (Pett et al., 2013) and higher dependence in performing activities in daily living (Van Schijndel-Speet et al., 2013). To reduce health inequalities and improve the health of people with intellectual disabilities, promotion of healthier lifestyles is important (Alesi and Pepi, 2015). Promotion of physical activity is one of the many health protective behaviours that may lead to a healthier lifestyle. Health conditions can be combatted with an increase in physical activity and taking an "exercise is medicine" approach. An "exercise is medicine" approach has been seen to be successful in the general population and has shown a linear relationship between physical activity and health status, with those maintaining an active lifestyle generally being healthier and living longer (Sallis, 2015; Thompson et al., 2020). People with intellectual disability can positively benefit from physical activity such as improved balance, muscular strength, aerobic capacity, gross motor function, and overall well-being or quality of life (Bartlo and Klein, 2011).

Despite some evidence that sedentary behaviour is a major factor causing ill health in people with intellectual disabilities there are gaps in knowledge (Dairo et al., 2016). In Ireland, the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing wave 3 study showed that, 85.8% people with an intellectual disability aged 40+ were sedentary or underactive. Though research over last decade has shown that the secondary ageing process can be partly slowed down or reversed by physical activity for people with Alzheimer's disease (AD) and cognitive decline (Buchman et al., 2007), but greater research is required to understand the positive impact of physical activity on older adults with intellectual disabilities and in particular, the scope for greater ownership and leadership by people with intellectual disability of their own health. Given the negative consequences of a

sedentary lifestyle, and greater risk of older adults with ID leading sedentary lives, the need for physical activity interventions is critical. As such health disparities identified in this population, can be targeted through efforts to increase physical activity levels among people with intellectual disability as they age.

Leadership among people with Intellectual Disabilities

The potential for people with intellectual disabilities to perform leadership roles in health and in particular in health promotion and physical activity, has received some but not substantial consideration. Peer mentoring programmes were found to bridge the gap between passive inclusion in a programme to having full meaningful participation (Spassiani et al., 2019). Also, long-term sustainability of health promotion programs and interventions was more likely in peer mentoring programmes as it involves peers translating knowledge directly to the community, rather than knowledge coming from agency staff and other professionals (Spassiani et al., 2019).

For people with intellectual disabilities, there is currently the “Special Olympics” Athlete leadership programme (<https://resources.specialolympics.org/leadership-excellence/athlete-leadership>). This programme provides athletes around the world with training in public speaking and opportunities to participate in governance in their local Special Olympics programmes and communities. Many of the athletes who participated have chosen to become Special Olympics coaches, allowing them to impart the lessons learned from leadership training to other athletes with intellectual disabilities in their communities. This has given people with intellectual disabilities a valued role within their community (Holder, 2015). However, there is a greater emphasis within Special Olympics on competitive sport and the programmes typically cater for a younger population. Special Olympics encourages individuals with intellectual disabilities (8+ years) to train and compete in any of the 30 summer and winter Olympic-type sports (Harada et al., 2011). Training and competition demonstrate capability and ability rather than winning. There is an emphasis and motto in the athlete oath: ‘Let me win. But if I cannot win, let me be brave in the attempt’ (Harada et al., 2011).

Stanish & Temple study (Stanish and Temple, 2012) found peer mentoring and peer-guided exercise training to be strongly associated with improved physical activity in adolescents with intellectual disabilities (Stanish and Temple, 2012). Adolescents with intellectual disabilities and typically developing peer partners provided mutual support during exercise sessions that included aerobic exercise, weight training and stretching activities. Participants demonstrated significant improvements in functional fitness. The peer-guided model also increased social supports and may encourage continued exercise participation (Stanish and Temple, 2012). There are other reported peer mentoring and leadership programmes where students with intellectual disabilities engaging in peer mentoring programmes offered by college students have increased the number of students with intellectual disabilities attending college (Farley et al., 2014).

Likewise, a mentored community-based exercise approach was taken with youths with disabilities in a study by Shields et al., 2018 (Shields et al., 2018). Quantitative and qualitative data was gathered to evaluate the programme’s success with youths with a range of disabilities such as Down syndrome, cerebral palsy, spina bifida, spinal cord injuries and autism. The program was overwhelmingly accepted by participants and their parents, who described it as enjoyable, fun and motivating, and fitness improved (Shields et al., 2018). Here too, a younger cohort of people with intellectual disabilities benefited from these programmes. There has been no comparable peer leadership programme focused on functional fitness and physical activity and specifically for the older people with intellectual disability.

The P-PALs Programme

The Physical Activity Leaders (PALs) concept is based on the principle of self-determination and seeks to empower older people to choose, plan and lead the recreational sports or physical activities they desire. PALs is the only physical activity peer leadership training for the general older population in Ireland. The programme is targeted at independently mobile, active older adults at all levels of physical fitness. Each workshop has a corresponding manual designed as a support for the PAL once they return to their peer group. The success of the PALs programme and broader Go for Life programme, is evident in the over 2,000 people trained to date as peer leaders; participation of nearly 300 from 24 counties in the 2016 Go for Life Games Day event and over 30,000 people annually taking part in activities funded by the Go for Life grant scheme

The PPALs programme reported in this paper builds upon the existing “go for life” and PALs approaches, tailored to give similar opportunities to older adults with intellectual disabilities. There is a focus on the individual with ID gaining leadership skills, promote confidence, motivation, self-determination and improve mental health through encouraging participation in community-based activities. A unique participant-led approach has resulted in a programme co-designed by persons with intellectual disabilities. The programme aims to

To date there are no peer-led programmes in Ireland that encourage older adults with intellectual disabilities (40+ years) to be physically active. Current training programmes are instructor and coach led.

Methodology

Study design

The Intellectual Disability Supplement to the Longitudinal Study on Ageing (IDS-TILDA), based within the School of Nursing and Midwifery, Trinity College Dublin, is the first national longitudinal study on ageing to include a cohort of people with intellectual disability which is run in tandem with the general population study. Over thirteen years, IDS-TILDA has provided essential data on the changes in the lives of people with an intellectual disability across of physical, mental and cognitive health, social participation and connectedness, health care utilisation and family caregiving measures.

The pilot PA study presented in this paper, draws participants from the IDS-TILDA study and worked collaboratively with the Trinity Sport Centre and Age & Opportunity to run the programme in Ireland.

The commitment was for participants to:

1. Complete a 6-week training programme;
2. Lead 5 PA sessions in a suitable location within the facilities of their disability service provider;
3. Complete objective and subjective health measures pre and post training (see [Table 1](#) and [Table 2](#) for description of measures);
4. Complete an evaluation survey at the end of training.

A person with intellectual disability was recruited to work on the project as an accessibility consultant and assisted in designing the manual and video training materials as well as participating

Table 1. Objective health measures

Test	Explanation
Height	measured to the nearest millimetre using a free-standing stadiometer or height measuring device. The height was used in the calculation of the participant's Body Mass Index (BMI).
Weight	Weight was measured to the nearest 100g using an Ultra slim digital scale. Weight was needed to calculate the participant's BMI.
Blood pressure	The blood pressure is measured in terms of millimetres of mercury (mmHg). For this test, the blood pressure will be measured using an automated sphygmomanometer.
Timed up & go	The "timed Up & Go" (TUG) test measures, in seconds, the time taken by an individual to stand up from a standard armchair (approximate seat height of 46 cm, arm height 65 cm), walk a distance of 3 meters (approximately 10 feet), turn, walk back to the chair, and sit down again.
Waist and hip circumference	The waist-to-hip ratio is a measure of distribution of body fat both subcutaneous and intra-abdominal. Studies suggest that this ratio is a predictor of health risk like the BMI (Ashwell and Gibson, 2016 ; Lam et al., 2015).
Hand Grip strength	Grip strength is a measure of muscular strength or the maximum force/tension generated by one's forearm muscles. It can be used as a screening tool for the measurement of upper body strength and overall strength. It is most useful when multiple measurements are taken over time to track performance (Bai et al., 2019)

in the training sessions and supporting with room set up and support within each session. Feedback was also gathered on an informal weekly basis in training and coffee breaks from the PPALs and their support workers, and this was used to update elements of the manual each week.

Recruitment

In total, 16 PPALs were recruited from 6 disability service providers to take part in the 6 week training programme in Ireland. One participant did not continue with the programme following completion of the 6-weeks training. Disability service providers engaged with the IDS-TILDA study within the Dublin and Kildare area, were contacted to recruit potential participants. At least one project gatekeeper and champion was identified within each service provider. These gatekeepers were a mix of support or key workers, or sport centre leads. These will be referred to as supporters throughout the paper. A total of 11 supporters engaged with the project. These gatekeepers identified people within their service who were in the 40+ age group, had an interest in sport and physical activity, who were interested in trying a leadership role, and could commit to the time to attend and deliver training. Two to three leaders were recruited from each of the 6 disability services.

Training programme description

Weekly 3-hour leadership training sessions were held in Trinity Sports centre and led by an experienced PALs trainer from Age & Opportunity.

The programme has 4 main components:

Table 2. Survey measures

RAPA	The RAPA (Topolski et al., 2006).was used as a means of assessing the levels of aerobic physical activity of the PPALs. Measures level and intensity of physical activity for aerobic exercise, strength and flexibility in line with recommendations made by the National Guidelines on Physical Activity in Ireland (DH, 2013). The survey was a nine-item questionnaire with the response options of yes or no to questions covering the range of levels of physical activity from sedentary to regular vigorous physical activity as well as strength training and flexibility as well as a brief description of three levels of physical activity (light, moderate, and vigorous) (Topolski et al., 2006).
IPAQ	The IPAQ (Lee et al., 2011) was carried out to analyses the intensity of physical activity the PPALs partake in daily. The IPAQ is an instrument designed primarily for population surveillance of adults. It has been developed for use in adults aged 15-69 years. There are 3 categories which accounted for physical activity domains in this survey: (Lee et al., 2011) 1. Inactive: The 'inactive' category represents the lowest levels of physical activity and PPALs who did not meet criteria for category 2 and category 3. 2. Minimally Active: represented 'minimally active' PPALs. To be considered for this category participants had to be 'sufficiently active' in one of the following 3 criteria: a. 3 or more days of vigorous activity for at least 20 minutes per day b. 5 or more days of moderate intensity activity or walking for at least 30 minutes per day c. 5 or more days of any combination of walking, moderate- intensity or vigorous intensity activities achieving a minimum of at least 600 MET –min/week. METs is defined as the amount of energy expended for activities. 3. HEPA Active: This represents the more active category. PPALs who are considered for this category had to exceed the minimum public health physical activity recommendations and therefore accumulate enough activity for a healthy lifestyle. This indicates that higher levels of participation can provide greater health benefits. To be considered for this category PPALs had to meet one of the following HEPA criteria: a. Vigorous intensity activity on at least 3 days achieving a minimum of at least 1500 Met minutes/week b. 7 or more days of any combination of walking, moderate intensity or vigorous intensity activities achieving a minimum of at least 3000 MET-minute/week.
Self-Efficacy for PA	The Self-Efficacy for Physical Activity scale (Peterson et al., 2009), was administered to all PPALs, to measure self-efficacy in terms of confidence to perform physical activity, and to overcome barriers towards physical activity. The research indicates that self-efficacy towards physical activity is a strong correlate of likelihood to engage in physical activity (Trost et al., 2003). In this study the PPALs were asked six questions with no, maybe and yes responses. The maximum score was 12, with the higher score indicating a higher self-efficacy towards physical activity.
Satisfaction survey	The satisfaction survey was self-designed by the researchers to measure the satisfaction of training, the trainer and the facilities as well as how satisfied the participants were when leading. These were filled in by the PPALs following the completion of leading the 5 sessions
Reflection sheets	The reflections sheets were filled in after training by the participant to measure the quality of the manual. Therefore, each of the participants filled in the reflection sheets 5 times.

1. Warm up- this is a chair-based section designed around movements and stretch in a seated position.
2. Walk about- this is a walking and movement section designed around walking briskly in one direction. Other movements included jumping, changing direction and going faster.
3. Working together- This was a games-based section. There were 5 different games the leaders could choose from. The minimum requirement was to choose one of the games per section. The games include equipment such as balls, frisbees, Scidil and a dance.
4. Warm Down: this was a chair-based section designed to cool down the body after the games.

Each week the amount of training by the PAL's trainer reduced and the amount of leadership of exercises by participants with intellectual disabilities increased. Each participant had a hard copy of the training manual and accompanying videos.

Once the leaders had delivered the 5 physical activity sessions at their disability centres, they were welcomed back to a refresher training session to encourage them to continue leading in their centres and community. This was held in October 2018 and 12 out of the 15 PPALs were in attendance. In total 3 out of the 6 centres expressed that they would support the PPALs to continue to lead in the disability centre or in the wider community, while the other 3 centres would look into methods to allow the programme to continue.

Data collection. Pre and post subjective and objective health measures were gathered in May 2018 and in September 2018.

Objective health measures. Objective health measures were taken at two time points (pre and post training) and included measures of height, weight, blood pressure, timed up & go, waist and hip circumference. All anthropometric measures were measured in a private setting with a qualified health professional, a supporter and the PPAL themselves. The suite of objective health measures are described in [Table 1](#).

Subjective health measures and evaluation data. Subjective health measures and self-completion physical activity and self-efficacy scales were completed through administration of a survey. The suite of measures included in the survey are described in [Table 2](#).

Surveys were completed by the PPALs with support from their supporters workers at the same time point as the objective health measures. The surveys were sent to the leaders in advance of the scheduled health measure days to be completed with the assistances of a support worker. In addition to the surveys, there were three sources of data that informed the evaluation of the programme.

Self-reflection diaries were completed by the leaders after each of the sessions they led in their centre. The reflection sheets included details of where the session took place, who led the session, how many attended the session, exactly what the PPALs did on the day of the session, as well as how they felt about each part of the session. The PPALs were asked if there was anything they would like to change for the next week or if they have any suggestions. This was to help the PPALs have ownership over their learning and future direction of the sessions including any additional supports that may be needed. These sheets were returned to the researcher with the post survey data and served as a key part of the overall project evaluation

Observational data and additional feedback was gathered through site visits to each of the participating centres. These were completed following the training sessions and between sessions 1-5 of the peer leadership element. During each site visit the researcher would observe how the

programme was being received in the centres and to see if changes or adaptations were needed in the training for the next phase of the pilot. *The fourth aspect of feedback involved*, a focus group which was held with supporters involved in the program. Five daycentres and 7 supporters were represented in the focus group. The supporters were asked the following questions:

1. Tell us about your experience of being involved in the PPALs programme?
2. From being involved in the programme, what are benefits for support workers, centre and individual participants?
3. If it was to run again in the future, what changes would you make?
4. How is the PPALs programme working in the centres?
5. What is needed to support you, the PPALs and centre to continue running the programme. Any other issues?

Additional feedback was sought from supporters to gather a greater understanding into how the PPALs programme was received in the centres. Focus groups were held with supporters in November 2018.

Data Analysis: Data was analysed using SPSS version 24 and graphs were collated in excel. The hypothesis was that people with ID can perform leadership roles in PA. It was hoped that the study would see improvement in physical activity, improvement in objective and subjective measures of health, and an improvement in confidence. Pre and Post comparisons, descriptive statistics and cross tabs were run

Results

Anthropometric measures

The mean average anthropometric measures pre and post training for the fifteen Irish PPALs are shown in [Table 1](#) ([Table 3](#)).

Overall, there was a reduction from 32 kg/m² to 25 kg/m² in BMI. Though the overall classification remains overweight but there is a significant reduction.

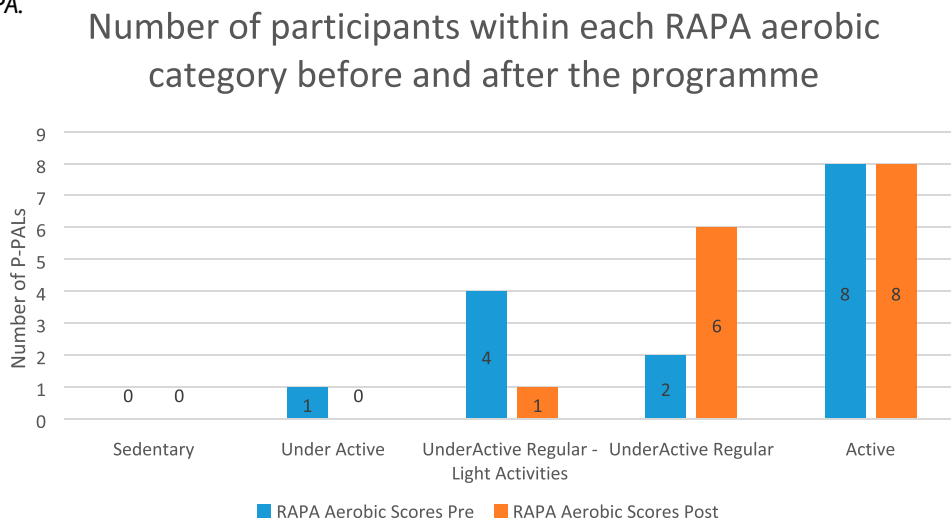
Table 3. Anthropometric Measures

Anthropometric Measures	Ireland Average	
	N=15	
	Pre	Post
Height	161	
Weight	82	79
BMI	32	25
Waist	106	92
Hip	110	97
Hand grip	50.5	53
TUG	10F (8.25M)	8F (7.5M)

There was a slight increase in total strength 50.5 kg to 53 kg for the hand grip test. The TUG test results for females showed a reduction in time from 10 sec to 8 sec. There was also an overall reduction for males from 8.25 sec pre intervention to 7.5 sec post intervention. This is a positive result.

Survey measures

RAPA.



Scoring for the first 7 items of the RAPA scale (Topolski et al., 2006), range from 1-7 with the respondent's score categorized into one of five levels of physical activity: 1 = sedentary, 2 = underactive, 3 = regular underactive (light activities), 4 = regular underactive, and 5 = regular active. Responses to the strength training and flexibility items are scored separately, with strength training = 1, flexibility = 2, or both = 3 (Topolski et al., 2006).

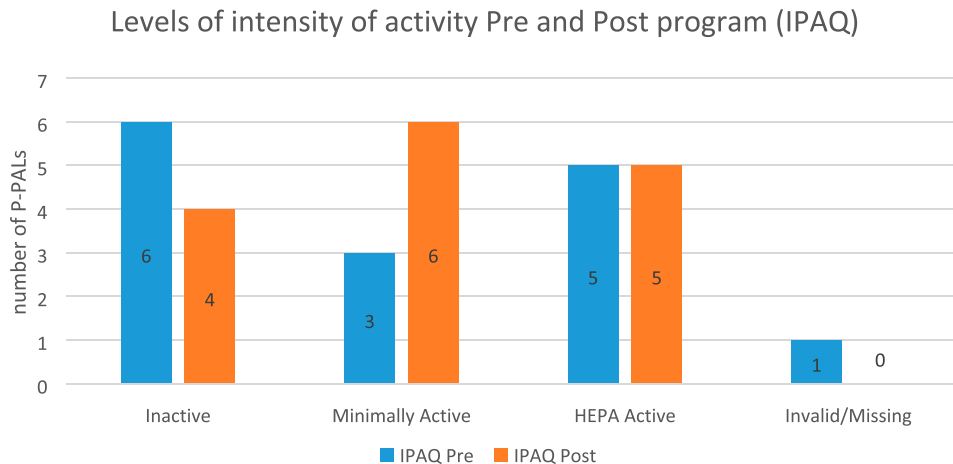
Our findings of the RAPA survey showed that 50% (n=8) of the PPALs were considered 'active' according to the RAPA before and after the programme. The number of participants in under-active/ regular activities category increased from 12.5% (n=2) PPALs before the programme began to 40% (n=6) after the programme was completed. This demonstrates that those who were under active still partook in "Light activities" and moved to participating in more "regular activities". As the sample was so small it was not possible to test if statistical differences were significant.

Self-efficacy (Peterson et al., 2009; Trost et al., 2003).

The PPALs mean score for self-efficacy was 6.88 (SD 3.54) before the training programme. This would indicate low self-efficacy towards physical activity amongst the participants.

Upon completion of leading 5 PA sessions, the PPAL's mean score for self-efficacy for physical activity increased to 7.33 (SD=2.55). These post training results indicate that 50% of the individual self-efficacy scores increased.

IPAQ (The International Physical Activity Questionnaire) (Lee et al., 2011)



The results showed that 5 PPALs fell into the HEPA active group both before and after the programme and six PPALs were ‘inactive’ before the training began. After the programme, four PPALs remained in the ‘inactive’ category. The number of PPALs in the “minimally active” category increased from 4 PPALs before the programme, to six PPALs after the programme finished.

Satisfaction Survey

Satisfaction with the training programme was measured through a post training survey, sent to participants once they had completed their 5 peer led sessions. Overall, feedback was positive across content, location, and structure of the programme, in addition to benefits felt.

Eighty percent of PPALs (n=12) thought the size of the training group was ‘*Just right*’. The remaining 20% found the group size to be ‘*too big*’ (n=3).

PPALs were asked ‘what they learned from the training at Trinity’, 56.6% (n=8) noted the training content (the new games and exercises) they learned during the training which included ‘*how to stretch*’ and ‘*different types of exercises such as walking, jumping and running*’. The majority, , 93.3% (n=14) of the P-PALs, were happy with the amount of PA in the sessions and the amount of theory in the training but when asked if they had ‘any ideas’ to make the training better, 26.6% (n=4) ‘would like more exercises/ games’.

Three PPALs commented on the leadership skills they developed during the training. They learned how ‘to be more confident’ and “to relax when leading a session’. Three other PPALs commented on “teamwork’ which again is an important skill when leading a session in pairs. Fifty percent (n=7) PPALs felt they were ‘very confident’ that they could lead a physical activity session. 21.4% (n=3) were ‘a little confident’ that they could lead a physical activity session, 14.3% were ‘confident’ and 2 PPALs were ‘a little not confident’ that they could lead a physical activity session.

Overall, the PPALs thought they were ‘very good’ leading the session with only two PPALs mentioning they ‘*done well but needed support*’. Another PPAL commented they were ‘Happy with it but found some exercises in the warmup part difficult to remember so used the book for support’. When PPALs were asked to comment on elements they could have done better responses included ‘*remembering the movements*’ and ‘*shouting louder so people could hear me*’.

Two PPALs commented that they gained ‘friendships’ while partaking in the PPALs training programme.

Reflection sheet findings

PPALs positively rated the delivery of their weekly sessions with , 93.3% (n=14) of stating that they thought the delivered session went well. When reflecting if there was anything different the PPALs would like to do for the next session, 46% (n=7) of the PPALs would *'like to be more prepared and have the day set up the day before for the class'*. Twenty percent (n=3) of the PPALs *'liked having the book with pictures to help remember the exercises if they forgot'*.

Among challenges encountered, two PPALs mentioned that after the second session they had to 'Change the venue of the class as some service users had difficulty with using the stairs.' Another two PPALs ran out of time for the 'Warm down' and declared 'I want to make sure they have enough time to include the warm down next week'. One of the PPALs mentioned that controlling the 'timing of the session was an issue' as well as having 'patience with the group doing the session'.

In response to 'if there was anything the PPALs would change for the next session' two of the PPALs noted how they *'share the lead'* during the session and thought it worked well. During the fourth session one of the PPALs commented that their class 'came up with a new move for the warmup', and four of the PPALs reported 'the participants and themselves had fun'.

During the fifth session, half of the PPALs commented *'I really enjoyed it'* and two of the PPALs asked for 'more training'. In the future it may be worth considering a refresher session at the mid-point of the 5 sessions.

Focus Group Findings

Feedback from the supporters focus group address x themes: the PPALs, training, leadership, benefits and logistical challenges.

Supporters who participated in the focus groups noted the following:

The PPALs. There was a general consensus that PPALs were *'really good leading the sessions'*. Three of the supporters commented that at the beginning of the programme the PPALs were *'very quiet and nervous'* and the PPALs required a lot of prompting but now *'the PPALs are very enthusiastic about the programme and leading'*. They were reported to be confident leading and really enjoying leading the sessions every week in the centre. One support commented that *'it's very positive feedback and no-one has a negative thing to say about the programme'*. The PPALs have also taken a sense of ownership of their role of being a leader *'they are very serious and there is no messing if you are a participant in the PPALs class'*.

Training. The supporters who attended the training said they were *'totally impressed'* by the training in Trinity College Dublin. Two of the supporters were unable to attend all the training sessions in Trinity and both were *'disappointed'* that they couldn't. They felt they were *'not giving the correct level of support'* to the P-PAL. Both made a point that there was a need for *'an additional support worker training day in the future'*.

The majority of supporters acknowledged that they found it difficult to find the correct balance between supporting the PPALs and leading the class for the PPALs. However, two of the supporters mentioned that due to staff shortages in the centre, there were times the PPALs had to lead the class and the supporters checked in every couple of minutes to see how the class was going. Reporting on two observed sessions one supporter stated: 'They were a little nervous at first as they didn't know the groups, they were teaching but we were able to prompt them until they became a bit more comfortable'.

Leadership Skills. In one particular centre the supporter mentioned how enthusiastic the PPALs were about leading the sessions in their centre and in the local community. As a result of leading the session in the community, PPALs *“went home that evening smiling from ear to ear and was enthusiastic about going into the community setting to lead more classes again in the future.”*

Benefits. Supporters mentioned how the PPALS have developed personal skills. One supporter mentioned *“their confidence has improved, and they take ownership. They have their equipment, and they have their manuals, and they have something that means it’s theirs.”*

There was also benefits to people from the disability centres who participated in the peer-led sessions each week. Supporters mentioned that by having the PPALS programme at their centre, it has given an opportunity for participants to get involved in a physical activity class where previously there were no options for older adults. Supporters commented on how excited participants were to take part in the classes on a weekly basis.

Logistical Challenges. Logistical challenges mentioned by supporters included problems with the timing of the training. Summer break for centres is typically mid-July and the PPALS pilot ran from May until July. The supporters recommended that training should start earlier in the year to allow time for the PPALs to participant in training and lead sessions. One support worker also mentioned that not all the PPALs attend the centre on the same days, which created challenges in supporting and re-enforcing the learning.

‘The PPALs don’t actually come to the sports centre on the same day so I had to do them separately to work with in their time limit so at the moment it was just that they did the 5 sessions’

Discussion

This pilot study was the first known programme to focus on developing leadership skills of older people with an intellectual disability through the mechanism of physical activity. There was a strong focus on self-determination, autonomy, citizen engagement and functional fitness as opposed to sport, based on the general population programme developed and delivered by Age and Opportunity in Ireland. Gathering data on participation and completion rates in the training programme, objective health measures (pre and post training), survey (subjective health and satisfaction data) and various qualitative elements, the paper presented the initial findings of the feasibility, of the peer mentoring leadership programme and the impact on the health, well-being and confidence of older people with intellectual disability who participated. .

Similar to other studies looking at adults with intellectual disabilities ([Hilgenkamp et al., 2012a, 2012b](#)) the results of this study showed a small reduction in weight, BMI and waist and hip circumference. In the long term these improvements have added benefits to the prevention of secondary health conditions. PA benefits overall health by reducing morbidity and mortality ([Warburton et al., 2006](#)). The reduction in time to complete the timed up and go test is an additional positive outcome.

The results of the RAPA showed more improvements with 50% of people remaining active. Active is defined as a minimum of either 30 minutes of moderate physical activities, 5 days a week or 20 minutes a day of vigorous physical activities, 3 days a week. The remaining 50% (n=8) of the PPALs fell into the “under-active” categories before the programme began. “Under active” is considered as someone who does some light or moderate physical activities, but not every week. “Under-active regular light activities” is defined as someone who does some light activity every week. “Under-active regular” is either someone who does moderate physical activities every week,

but less than 30 minutes a day, or five days a week. Although this is an improvement further intervention is needed as sedentary behaviour has been identified as the fourth leading risk factor for mortality (6% of deaths) globally.

The intensity of the exercise within this pilot programme was on functional fitness rather than high intensity sport and exercise, meaning that large changes in objective health measures were not expected and not the main goal of the programme. The focus is on fitness, citizen engagement and self-determination. Thus, some of the most interesting findings from this pilot programme relate to the positive impact on soft measures experienced by the PPALs.

The pilot demonstrated that older people with intellectual disabilities, can be leaders, that they want to be leaders and want to continue to be leaders. In addition, the data (both survey and qualitative) illustrates the improvement in overall well-being, self-confidence and independence experienced by the leaders and how the leadership and confidence skills developed have reverberated across other parts of the leader's lives.

Additionally, the results of the satisfaction data demonstrate changes in attitudes, improvements in perceptions to physical activity and gained life skills such as teamwork and this is in line with similar studies by (Spassiani et al., 2019).

The improvement in confidence and interpersonal development for the leaders in this programme has definitely been the most empowering part of this study with supporters commenting *'It's a great programme. The PPALs have really grown in confidence. Some have even started leading in other classes such as yoga'*.

Limitations

This was a pilot project with a small sample of people with intellectual disability in a small geographical area. The small sample size was sufficient to demonstrate the feasibility of people with intellectual disabilities as physical activity leaders and provides strong evidence for future expansion of the programme. There are plans to extend the programme across Ireland, continued roll out in Spain and newly developed for Germany.

As a co-design project, the training materials (manual and video) were not available to the prospective leaders at the outset as changes were being made throughout in response to the feedback from leaders. Future training will benefit from the materials being ready to distribute and support the leaders learning from the outset.

With regards to pre and post measures, the data was captured at two time points within a short time period. This was a factor of the requirements for reporting to the funder within a specific time frame. Therefore, the results should be considered indicative, rather than conclusive. A longer time frame with repeated data points at 6 months and a year would provide additional insight into the impact of participation in this training. In addition, blood pressure results are not reported as it was not completed for sufficient number of participants. The focus is on functional fitness and leadership, rather than high intensity sport and exercise and so the physical health improvements may not be as big as originally anticipated.

Conclusion

Though people with intellectual disability have been shown to be more likely to experience sedentary behaviour and have greater risk of poor health outcomes. There is less evidence on the extent to which people with intellectual disability can engage in preventative health practices and in particular, their role as leaders in preventative health and physical activity. The pilot project shows

the capacity for people ageing with intellectual disability to co-design and co-deliver functional fitness programmes, and to continue to lead delivery of such programmes with their peers. The changes in objective health measures were minimal but likely due to the short time frame between data points. However, the subjective or soft outcomes were immense, including increases in confidence, independence, and voice. This study demonstrates feasibility of the programme on a small scale and future development on a national level should be supported.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by EIT Health

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