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The lifestyle behaviours of young adults with intellectual disabilities transitioning from school to adulthood: a feasibility study.

Abstract

Background: In the general population, the transition from adolescence to adulthood has been identified as a ‘high-risk’ period for weight gain. There has been no research examining health behaviours over this transition in adults with intellectual disabilities (ID).

Methods/design: The feasibility of recruitment, retention and relevant health behaviours were measured in 31 adolescents with mild-moderate ID. Anthropometric, objective physical activity, dietary and self-determination measures were collected over a 12-month transitional period from school to adulthood.

Results: Key results suggest weight and BMI increased significantly from month 6 to month 12 (p=0.044 and p=0.043). Waist circumference increased significantly from baseline to month 12 (p=0.049), and from month 6 to month 12 (p=0.03).

Discussion: Recruiting and retaining young adults with ID over a 12 month health behaviour study is feasible. The data indicates the transition from school to adulthood may be the start of a high- risk period for weight gain.

Keywords: Intellectual disabilities, Lifestyle behaviours, Physical activity, Diet, Transition, and Weight gain prevention

Introduction

There is a prolific body of evidence showing the negative effects of obesity on health (Guh et al., 2009; Whitlock, O'Connor, Williams, Beil, & Lutz, 2010; WHO., 2013). Adults with intellectual disabilities (ID) have significantly higher levels of obesity than the general population (Bhaumik, Watson, Thorp, Tyrer, & McGrother, 2008; Melville et al., 2008) and research shows increased cardio-metabolic risk factors in this population (Wallén et al., 2009). There is also evidence indicating young people with intellectual disabilities have higher rates of obesity than typically developing young people. Population based studies from the general population suggest that the five year transitional period between adolescence and young adulthood is known to be a period of increased risk for the development of obesity (Gordon-Larsen, Adair, Nelson, & Popkin, 2004), unhealthy diet and low physical activity levels (M. C. Nelson, Story, Larson, Neumark-Sztainer, & Lytle, 2008). Transitioning from school to adulthood often requires adapting to a less structured environment. Research suggests this change in environment is likely to be more pronounced for individuals with intellectual disabilities, with up to 75% of individuals underemployed (part-time workers who would prefer to be full time) or unemployed up to 3 years after leaving school (Luftig & Muthert, 2005). This may result in more time spent sedentary at home, or in a residential day centre setting.

Parents become less involved in their child’s lifestyle behaviours (e.g. dietary choices, physical activity), as they move into adulthood (Robinson, 2000). For individuals with ID, lifestyle choices are also influenced by paid carers, which may have a negative impact on health behaviours. For example, recent research suggests parents and carers’ own lack of motivation or time to be active can act as a barrier when supporting an individual with an intellectual disability to participate in physical activity (Spanos et al., 2012). Young people, with and without intellectual disabilities, often choose not to eat a balanced diet and opt for takeaway and junk food when given the choice (Stevens, 2017). In addition, a growing international literature base suggests that individuals with intellectual disabilities have low levels of self-determination, a measure to determine the process used by the individual to control their own life (Stancliffe & Parmenter, 1999; Wehmeyer, Kelchner, & Richards, 1996; Wehmeyer & Metzler, 1995). Therefore, choices about lifestyle behaviours are likely to be more complex and heavily influenced by others, than in the general population. Currently, there are no published studies examining the lifestyle behaviours of young people with intellectual disabilities during their transition to adulthood. Since the prevalence of obesity is significantly higher in individuals with intellectual disabilities, than in the general population (Bhaumik et al., 2008; Melville et al., 2008), it seems likely this transition would be a more pronounced high- risk period for young people with intellectual disabilities to experience weight gain. A recent systematic review highlights there has been no research to date which has monitored change in weight, or lifestyle behaviours relevant to health with this population (Young-Southward, Philo, & Cooper, 2017).

The Medical Research Council (MRC) framework for developing and evaluating complex interventions strongly advises carrying out feasibility and pilot work prior to carrying out larger scale randomised control trials (Craig et al., 2008). Assessing recruitment and retention rates in a feasibility study is an important first step prior to designing and implementing a trial. Therefore, in keeping with phases 1 and 2 of the MRC framework, the aim of this mixed method study was to assess the feasibility of recruiting and retaining young people with intellectual disabilities to a lifestyle behaviour study. In addition, exploring young people’s self-determination and the context of their lives is useful for developing future tailored and effective lifestyle behaviour interventions.

Aims

1. What strategies are most effective to recruit young adults with intellectual disabilities to take part in a research study over the transition period?
2. How effective is retention of participants during a 12-month longitudinal study of young adults with intellectual disabilities?
3. Can lifestyle behaviour outcomes (weight, diet, physical activity) and self-determination be measured and followed up over time?
4. What are the environmental mediators of self-determination that need to be considered in relation to lifestyle behaviours and health, at the time of transition?
5. Are DINE and a multiple recall questionnaire (24 hour recall) appropriate dietary measures for young adults with intellectual disabilities?

Feasibility design

Inclusion criteria

Participants over 16 years of age who had a mild-moderate intellectual disability were invited to join the study (those with specific disorders of developmental delay e.g. speech and language delay, dyslexia or autism spectrum disorder without an intellectual disability were not included in the study). Individuals who were not in their final year of school and were not independently ambulatory were excluded from the study. Participants were recruited from additional support need (ASN) schools in Greater Glasgow and Clyde and Lanarkshire, based on the above selection criteria. Ethical approval was granted by the University of Glasgow ethics committee.

Procedure

Thirty-six young adults with intellectual disabilities were invited to participate in the research. Thirty-one were eligible and consented to the research. The sample size was based on recommendations from authors specialising in feasibility and pilot studies (Browne, 1995; Lancaster, Dodd, & Williamson, 2004). Recruitment was carried out from December 2014 to June 2015, guided by a recruitment strategy (Foster et al., 2011; Mitchell et al., 2013; S Treweek et al., 2010). Researchers have identified the need for a recruitment strategy, particularly in RCT's (Foster et al., 2011; S. Treweek et al., 2010). Therefore, it was important to develop a strategy at the feasibility stage of this work to determine effective recruitment points for future studies. A strategy was designed to guide the recruitment process, based on the framework provided by Foster et al. (2011) which identifies four key stages in recruitment. The primary recruitment pathway was ASN schools, with the full sample recruited from four ASN schools in Greater Glasgow and Clyde and Lanarkshire. The researcher contacted each school head teacher to provide information about the study and offer the opportunity of participation. The teachers identified which pupils met the inclusion criteria and arranged a date for the researcher to deliver an information session about the study. Interested pupils were provided with an information pack, which was designed and piloted for individuals with mild-moderate intellectual disabilities. The researcher also read the information on the information sheets aloud. Participants who were interested in participating in the study were invited to either inform the researcher verbally during the information session or return the information tear-off slip to their teacher. The researcher ensured participants had the opportunity to ask any questions and that they understood their involvement in the study. The researcher was careful to communicate clearly, using appropriate language for the level of intellectual disability and was patient and empathic in her interactions with the young people. Individuals aged 16 years and over, who are deemed to have capacity to consent to research, do not normally need parental consent to participate in research studies. However, participants in this study were encouraged to discuss the study with their family. The researcher ensured all participants had capacity to consent to the research by asking a variety of questions to ascertain that they understood what was being asked of them (e.g. can you tell me what this study is about? do you know what this belt (accelerometer) is for? Who decides if you want to take part? What do you do if you don't want to take part anymore?). All participants who were deemed to have capacity to consent, and met the inclusion criteria, were included in the study.

Participants who participated in the study completed the measures detailed below. The researcher assisted the participants with all aspects of the study measures, including setting up the equipment and reading the questionnaires aloud to participations and recording responses. Overall, the quantitative measures together took around 60 minutes to complete. Changes in dietary patterns and self-determination were analysed between baseline, six month and 12 months to assess for any trends over time. A nested qualitative study, involving individual interviews, was also carried out with these participants. The results are reported elsewhere (Stevens et al, 2017).

Quantitative outcome measures

The following measures were completed by participants at baseline, six and 12-month follow-up.

Anthropometric Measurements

All anthropometric measurements were collected using standard procedures in accordance with the International Standards for Anthropometric Assessment (Stewart, Marfell-Jones, Olds, & De Ridder, 2011), with the participant wearing light clothes and without shoes. All measurements were made in duplicate and a final mean value calculated. Weight in kilograms (kg) was measured to the nearest 100 grams. Height in metres (m) was measured to the nearest 1millimetre (mm). The height (m) and weight (kg) were used to calculate body mass index (BMI) using the formula: BMI = weight/height ^{2} (kg/m^2). Waist and hip circumference were measured to the nearest 0.5 centimetre (cm).

Physical Activity Measurement

Physical activity was measured objectively using ActiGraph GT3X accelerometers (ActiGraph, Pensacola, FL). Participants were instructed how to wear the monitor and were also given a wear instruction leaflet to take home to parents. Participants were asked to wear the accelerometer for seven days at the three time points of baseline, six and twelve months, on the right hip, attached with a belt, during all waking hours; except when showering, bathing or swimming. The participants were offered a range of 'tips' to help them to remember to wear the accelerometer. E.g. hang it on the bedroom door, leave it on the pile of clothes to be worn the following day. Previous research by the authors indicates reasonable compliance of wearing the accelerometers for the wear time specified (Melville et al., 2016). The monitors are small, lightweight and are worn round the waist. Clothing is worn over the top of the monitor minimising the visibility of the device. The researcher advised that participants should continue with their normal patterns of participation in physical activity. The monitor does not come with any safety risks and was activated by the researcher at the study visit. Each stage of data collection consisted of two visits to each participant, roughly one week apart. At the second visit, the researcher checked the accelerometer wear time using the ActiLife software (http://actigraphcorp.com). If the device had not been worn for at least six hours a day, for three days, the researcher invited the participant to wear the accelerometer for a second week. In such cases, a third visit was arranged to collect the device.

Accelerometry is a valid measure of physical activity (Reilly et al., 2008) and has been widely used in young adults with intellectual disabilities (Hinckson & Curtis, 2013). A seven day monitoring period also provides reliable (ICC = 0.76 - 0.86) estimates of physical activity, including weekday and weekend differences, in young adults (Trost, 2005). The ActiGraph quantifies physical activity in counts/minute, which can be used to estimate time spent in sedentary, light, moderate and vigorous intensity activity, and can enable the calculation of activity energy expenditure (Youngwon, Beets, & Welk, 2012). In keeping with guidelines on the validity of accelerometer data, the minimum data requirement was six hours of data on at least three days from seven, to ensure a valid measure of physical activity levels (Basterfield, 2011; Janssen, 2015).

Accelerometer data was downloaded to ActiLife software (version 6.4.3). Data that did not meet the minimum wear time was excluded from analysis. The primary outcome measure of % of daily time spent in light, moderate to vigorous (MVPA) and sedentary behaviour was determined. As there are currently no validated cut points for young adults with intellectual disabilities, two different cut points were employed in this study to allow comparison. Firstly, cut points that have been calibrated and validated in adolescents were employed: sedentary (<100 cpm) (Evenson, Catellier, Karminder, Ondrak, & McMurray, 2008) and MVPA (≥3200 cpm) (Puyau, Adolph, Vohra, & Butte, 2002). In addition, cut points that have recently been developed with children with intellectual disabilities sedentary and MVPA (McGarty AM, 2016) were all used to examine amount and % of time spent in each intensity. A macro was used to calculate average time worn per day. This was designed by an expert in accelerometer data who has developed and tested this extensively with various populations (Janssen, 2015). To ensure that sleep data was not included in the analysis, data recorded between midnight and 6am was excluded from the analysis, for all participants, as recommended by (Janssen, 2015). The researchers also checked the data visually to check if any participants that had worn the accelerometer overnight slept past 6am. In such cases, this was manually adjusted in the macro and removed until the participant was awake and active. Periods of consecutive zeros were kept in the data as assumptions were not made to define periods as non-wear or sedentary behaviour. If accelerometers were worn for less than 7 days, average time in PA and sedentary behaviour was adjusted and calculated for each valid day. Data was analysed only for participants who met the minimum wear time at all three time points. In total, full accelerometer data was analysed from baseline to 6 months for 15 participants and baseline to 12 months for 14 participants.

Dietary habits

The feasibility of measuring dietary habits was assessed using two different methods. Usual dietary patterns were captured using the “DINE” food frequency questionnaire (Roe, 1994). The DINE questionnaire was designed to make a quick initial assessment of the amount of total fat and dietary fibre in an individual’s usual diet. The questionnaire lists 19 foods or food groups which have been pre-scored according to the relative amount of fat or fibre contained in an average portion of the food. These scores are then weighted by the daily or weekly frequency of intake reported by the respondent, and summed to give overall fat and fibre scores. This allows the researcher to categorise a diet immediately into low, medium, or high fat and fibre intake. An additional question provides an index of the balance of saturated and unsaturated fat in the diet. This questionnaire can either be scored by the participant or researcher. For this population group, the researcher read the questions aloud to the participant, then scored each food group and provided feedback on their scores. The DINE method can be used by researchers without nutrition expertise to identify problem food groups and to direct discussion about beneficial dietary changes.

Patterns of diet across the study were also estimated using the 24 Hour Recall method. This consisted of the researcher asking the participant to remember in detail all the food and drink they consumed during the past 24 hours. The researcher asked participants to recall as much as possible and wrote down the respondent’s answers. As a retrospective method it relies on an accurate memory of intake, reliability of the respondent not to under / misreport, and an ability to estimate portion size. Individuals with severe to profound intellectual disabilities may not be able to articulate a reliable account of what has been consumed in a questionnaire/interview format, however, it was unknown if this was also true for those with mild-moderate intellectual disabilities, prior to carrying out this study. Currently, there is no published research which has explored the feasibility of using these dietary measures with individuals with mild-moderate intellectual disabilities; therefore an important component of this feasibility study was to examine the reliability and validity of these measures. Individual interviews also provided contextual information concerning the individuals’ autonomy and choice about diet, meal and snacking patterns, source of foods, and with whom meals are eaten. Pre-transition qualitative findings are available at (Stevens et al, 2017)

Self-determination

The feasibility of measuring levels of self-determination using the Choice Questionnaire (Stancliffe & Parmenter, 1999) was examined. This 26 item questionnaire is designed to measure the degree of self-determination available to individuals with intellectual disabilities. The measure includes questions about home life, staff (family), money and spending, health, social activities, community access, personal relationships, work/day activities, and overall self-determination. The scale has been shown to have sound reliability, validity, satisfactory test-retest reliability, internal consistency, interrater agreement, inter score agreement, content validity, concurrent validity and construct validity (Stancliffe & Parmenter, 1999).

Construct validity can be assessed by administering a questionnaire with groups who differ with respect to the construct which the questionnaire claims to measure. The authors of this questionnaire suggest that an individual's living environment is related to their choice and autonomy (Abery, 1996; Stancliffe & Wehmeyer, 1995). Therefore, they used the measure to discriminate between two groups who were living in different environments (semi-independent vs group homes) comparing total scores form the choice questionnaire with results from a t-test. Results suggested that those in semi-independent homes scored higher in the choice questionnaire, both in self-report t(24)= 4.26,p=.0001, and for staff reports, t(37.8)=5.30,p<.00005 suggesting more autonomy in their lives.

Data analysis

As this is a feasibility and pilot study, quantitative outcomes provide *preliminary* evidence of changes during the transition from school into adulthood, across the three time points. The results of this study will assist the authors in the calculation of the sample size required for a future full-scale longitudinal study. Descriptive statistics are provided as mean (standard deviation) for continuous variables and number and percentage for categorical variables. Changes in outcomes between time points are compared using paired t-tests. Statistical analyses were carried out using R for windows software.

Results

1. Recruitment, retention and adherence to study

The recruitment and retention rates of the study suggest that participants were able and willing to participate in all aspects of data collection. The goal of recruiting at least 30 young people with ID was achieved through four ASN schools (n=31), which was identified as a key recruitment point in the recruitment strategy. The mean age of participants was 17.1 years, with 71% male (see Table 1). In total, valid accelerometer data was available for 100% participants at baseline, 65% at 6 month follow up and 61% at 12 month follow up (Fig. 1). The proportion of participants who completed 12 month appointments was 19 (61%) (although only 14 participants had completed accelerometer data sets for baseline to 6 months, and 15 participants for baseline and 12 month time points). There were no differences in baseline characteristics between participants lost to follow up and completers. All participant visits were carried out one to one, at participants schools (baseline) or homes (6 and 12 months).

Table 1. Participants demographics and baseline characteristics

	N(missing)	Mean (SD)*
Age (years)	30 (1)	17.1 (0.63)
Gender, n(%)	31 (0)	
Male		22 (71%)
Female		9 (29%)
Height (m)	30 (1)	1.67 (0.09)
Weight (kg)	28 (3)	63.3 (10.94)
Body mass index (kg/m^2)	28 (3)	22.8 (4.53)
Waist circumference (cm)	26 (5)	81.9 (11.38)
Hip circumference (cm)	26 (5)	98.9 (7.97)

*Unless otherwise stated.

2. Feasibility of measures

Physical Activity Measurement

Previous research has found mixed results on compliance of accelerometer wear with adolescents with intellectual disabilities (Hinckson & Curtis, 2013; McGarty, Penpraze, & Melville, 2014). Previous evidence suggests disadvantaged subjects are at high risk of nonresponse in follow-up and longitudinal studies (Hough, Tarke, Renker, Shields, & Glatstein, 1996; Navratil, Green, Loeber, & Lahey, 1994) with some attrition rates 30% to 60% attrition over a 1- to 2-y follow-up period (Nelson, Deess, & Allen, 1999; Visher, Kachnowski, Vigne, & Travis, 2004). In this study, around 10% of individuals required two or three attempts of wearing the accelerometer to provide enough data for inclusion in the study. Often, this was due to young people forgetting to wear the device and parents forgetting to remind their son or daughter to wear it. The majority of participants reported no problems or discomfort wearing the accelerometer the device was worn on average for 5 days. A few participants (around 5%) requested to wear the device for longer than a week, in such cases the accelerometer was offered for 2 weeks, but only the first week of activity was used. The majority of participant's were keen to see their activity graphs on the actigraph software on the researchers' laptop, when the researcher visited to collect the device, suggesting engagement in the study and findings.

Dietary measures

The dietary questionnaire (DINE) and 24 hour recall were not considered to be an accurate measure of collecting dietary information with this population. Participants frequently struggled to quantify amount of food and drink consumed. In addition, there often appeared to be confusion about certain types of food, and difficulty with remembering how often these were typically eaten. When parents were present during the data collection visit, they often disagreed with what the participant reported. While parents' accounts could also be inaccurate, or reflect a wish to portray a healthier family diet, it suggests there may be a problem with the reliability of the measures. These questionnaires were, however, useful for providing contextual information that could be followed up in individual interviews. As the 24 hour recall data was not quantifiable (only descriptive information is provided), only the DINE questionnaire data was analysed.

Self- determination measure

The Choice Questionnaire was developed for individuals with intellectual disabilities, therefore this measure appeared to be feasible to use in this population, over the transition from school to adulthood; however, some of the questions require to be adapted. As all of the participants in this study lived at home with parents/guardians or in residential homes, the questions relating to paid carers were not relevant. In addition, the questions about alcohol, pubs and gambling were also not relevant to individuals under 18, and participants often appeared confused when they were asked about participating in these activities. Reflections from the researcher suggest that participants were unsure how to answer such questions- perhaps worried they would give the 'wrong' answer. Similarly, above we mention the conflicting answers between parents and participants for dietary responses. These experiences highlight the issues with self-report data, which can result in response bias. This may be even more prevalent in the lifestyle behaviour field and in vulnerable populations.

3. Preliminary evidence of changes in lifestyle behaviours over time

There was no significant change in time (% and minutes) spent in sedentary, or in light PA from baseline to 6 months, from baseline to 12 months or from 6 months to 12 months. There was, however, a significant increase in both of the accelerometry cut points used (see measures section for information) for minutes in MVPA from baseline to month 6 (p=0.043) but this was not significant when % were calculated, which is the measure typically reported (see Tables 2-4 below).

Weight, BMI and hip circumference increased, on average, from baseline to month 12 but these changes were not significant. The data also shows a large range of BMIs in the sample, highlighting individuals with intellectual disabilities are a heterogeneous group. Weight and BMI increased significantly on average from month 6 to month 12 (respectively p=0.044 and p=0.043). Waist circumferences increased, on average, significantly from baseline to month 12 (p=0.049), and also from month 6 to month 12 (p=0.03). The unsaturated fat score was the only dietary measure to decrease, on average, from baseline to month 12 (p=0.022), and also from month 6 to month 12 (p=0.04), based on the DINE questionnaire. There was no overall significant change in the Choice Questionnaire (Stancliffe & Parmenter, 1999) between the visits.

Table 2: Change in outcomes at 6 months from baseline

Outcome	N	Baseline Mean (SD)	6 months Mean (SD)	Mean difference (95% CI)	P-value
Anthropometry measurements					
Weight (kg)	18	64.2 (9.72)	64.5 (9.58)	0.25 (-1.36, 1.85)	0.749
BMI (kg/m^2)	17	21.7 (2.6)	22 (2.7)	0.31 (-0.25,0.87)	0.262
Waist circumference (cm)	15	82.9 (9.6)	85.8 (9.8)	2.88 (-0.13,5.9)	0.059
Hip circumference (cm)	15	99.4 (6.5)	105.9 (19.9)	6.52 (-2.37,15.41)	0.138
Dietary measurements DINE					
Fiber	19	27.8 (13.1)	22.3 (10.7)	-5.58 (-11.72,0.56)	0.072
Fat	17	29.9 (13.8)	35.2 (8.4)	5.29 (-1.23,11.82)	0.105
Unsaturated Fat	4	11 (2)	8 (3.3)	-3 (-6.18,0.18)	0.058
Choice measure					
Total choice score	18	46.3 (11.7)	50.1 (14.7)	3.83 (-2.95,10.62)	0.249
Accelerometer measurements (McGarty)					
% time sedentary	15	81.3 (6.4)	79.2 (7.1)	-2.1 (-4.39,0.18)	0.068
% time light PA	15	5.5 (1.5)	5.8 (1.3)	0.35 (-0.35,1.05)	0.301
% mod to vig	15	13.3 (5.6)	15 (6.3)	1.76 (-0.29,3.8)	0.087

Data only reported for participants with data at both baseline and 6 months data.

*significant (p<=0.05)

Table 3: Change in outcomes at 12 months from baseline

Outcome	N	Baseline Mean (SD)	12 months Mean (SD)	Mean difference (95% CI)	P-value
Anthropometry measurements					
Weight (kg)	16	64.5 (9.9)	66.3 (10)	1.86 (-0.59,4.31)	0.126
BMI (kg/m^2)	16	22.1 (3.2)	22.9 (3.1)	0.74 (-0.1,1.58)	0.079
Waist circumference (cm)	13	83.9 (9.8)	88.9 (9.3)	4.95 (0.03,9.87)	0.049*
Hip circumference (cm)	13	99.2 (6.8)	100.3 (6.8)	1.16 (-1.34,3.65)	0.332
Dietary measurements DINE					
Fiber	17	28.8 (12.6)	24.3 (9.7)	-4.53 (-11.75,2.69)	0.202
Fat	17	30.7 (12.9)	31.8 (8)	1.06 (-4.8,6.92)	0.707
Unsaturated Fat	4	11 (2)	5.2 (2.5)	-5.75 (-9.93,-1.57)	0.022*
Choice measure					
Total choice score	18	46.8 (11.7)	47.6 (19.5)	0.78 (-9.52,11.07)	0.875
Accelerometer measurements (McGarty)					
% time sedentary	14	82.2 (6)	81.9 (6.7)	-0.33 (-3.26,2.61)	0.814
% time light PA	14	5.2 (1.2)	5.5 (1.7)	0.3 (-0.58,1.17)	0.477
% mod to vig	14	12.6 (5.4)	12.6 (5.7)	0.03 (-2.55,2.61)	0.98

Data only reported for participants with data at both baseline and 12 months data.

*significant (p<=0.05)

Table 4: Change in outcomes at 12 months from 6 months

Outcome	N	6 months Mean (SD)	12 months Mean (SD)	Mean difference (95% CI)	P-value
Anthropometry measurements					
Weight (kg)	17	65.8 (11)	67.6 (10.9)	1.81 (0.05,3.56)	0.044*
BMI (kg/m^2)	16	22.5 (3.8)	23.1 (3.6)	0.6 (0.02,1.19)	0.043*
Waist circumference (cm)	17	84.9 (9.7)	88.2 (9.3)	3.31 (0.36,6.25)	0.03*
Hip circumference (cm)	17	104.2 (19.3)	100.1 (6.7)	-4.16 (-13.15,4.82)	0.34
Dietary measurements DINE					
Fiber	17	21.8 (10.7)	24.3 (9.7)	2.53 (-4.04,9.1)	0.427
Fat	17	35.6 (8.9)	33.4 (6.7)	-2.2 (-6.7,2.3)	0.312
Unsaturated Fat	9	8.1 (2.5)	5.9 (2.8)	-2.22 (-4.32,-0.12)	0.04*
Choice measure					
Total choice score	17	49.8 (14.7)	54 (9.5)	4.24 (-0.22,8.69)	0.061
Accelerometer measurements (McGarty)					
% time sedentary	13	80.3 (7.4)	81.6 (6.4)	1.26 (-2,4.52)	0.415
% time light PA	13	5.6 (1.3)	5.4 (1.7)	-0.24 (-1.23,0.75)	0.604
% mod to vig	13	14.1 (6.5)	13 (5.3)	-1.02 (-3.64,1.6)	0.412

Data only reported for participants with data at both baseline and 12 months data.

*significant (p<=0.05)

Discussion

Overall, the results of this study suggest recruitment was feasible with higher retention than similar studies with this population. Typically, researchers report less than 50% retention rates in other disadvantaged and vulnerable groups (Hough et al., 1996; McDermott et al., 2012; Navratil et al., 1994). Generally, participants complied with the data collection in the study, including the accelerometer wear time instructions. Some individuals required two or three attempts of wearing the accelerometer to provide enough data for inclusion in the study. This suggests a protocol for minimum wear time, which includes a reminder service from a researcher, is required when working with individuals with intellectual disabilities.

While the primary aim of the study was to test feasibility, a secondary aim was to assess if there was any initial indication of change over the transition period. The anthropometric results show increased weight, BMI and hip circumference (although not significant) from baseline to 12 months, with a significant increase in waist circumference from baseline to 12 months. Major metabolic cardiovascular risk factors (high blood pressure, plasma lipids, insulin resistance) can be evidenced through both BMI and waist to hip ratio (Lean, Han, & Morrison, 1995). In addition, waist circumference measures the body fat located intra-abdominally, as opposed to sub-cutaneous, therefore waist circumference can be said to be the best indicator of changes in intra-abdominal fat (Lean et al., 1995). Therefore, a significant change in waist circumference from leaving school to adulthood may indicate an increase in intra-abdominal body fat, for these participants. The mean weight change at six months is 0.25 kg, but this is much higher at 12 months (1.8 kg), suggesting the longer the participants were out of the educational system, the faster their weight gain. Previous research with adults who have transitioned from employment to unemployment also indicates strong associations with excess weight gain (Monsivais, Martin, Suhrcke, Forouhi, & Wareham, 2015).

It is widely acknowledged that there are limitations with the self-report dietary data, with researchers questioning the validity and reliability of participant's reports of daily consumption (Mitka, 2013). Evidence suggests that participants often underreport caloric intake or overstate the amount of the 'healthy' foods they consume, even presenting caloric intake responses that are not physiologically possible (Archer, Hand, & Blair, 2013). In the current study, the validity of the dietary measures are also questionable. There was often inconsistency in reporting intake, which may be associated with cognitive impairments or difficulty remembering, or it may be that 'favourable' dietary patterns/choices were provided to please the researcher. In addition, some parents would listen in on the questions asked or participants would ask them for the 'correct' answer. This often resulted in conflicting answers about what was/is eaten. This may reflect the significant decrease in self-reported unsaturated or 'good fat' at month 6 and 12, despite significant increase in objective measures of BMI, weight and waist circumference from month 6 to 12. At months 6 and 12 data was collected at participants' homes with a parent present, whereas baseline measures were collected at school, without parental input. Thus, the dietary results from the current study should be interpreted with caution.

The choice questionnaire was used to assess if the degree of choice available to young people with intellectual disability, changed over the transition period. The results suggest that degree of choice did not appear to change significantly over time. This study is to the first, to our knowledge, to pilot this questionnaire with an adolescent population. With the adaptation of a few questions, this measure appears to be feasible for assessing trends over time in an adolescent population.

Strengths and limitations

A major strength of the study is the use of subjective and objective measures over three time points and the inclusion of a 12 month follow-up measure. In addition, recruiting from ASN schools in Greater Glasgow and Lanarkshire was an effective way to reach the target sample size, thus showing a successful recruitment strategy. However, the researchers acknowledge that better strategies could have been implemented for retaining participants throughout the duration of the study. While efforts were made from the researcher and schools to invite parents to an evening information session, this was not well attended. Scheduling an information session before or after an existing parents evening would have been a more practical way to include parents from the start of the research. The face-to-face rapport with the parents from these early social interactions may have resulted in a stronger affiliation when trying to organise post transition data collection visits at their home. This may reflect the high drop-out rate from baseline to six months, as the researcher often struggled to get in contact with participants once they had left school. Having an additional contact number or email address for parents would likely have helped this process.

In addition, many of the participants in the study left school and went on to full time education (a college course on life skills was particularly popular), therefore it may be that this transition to adulthood is essentially delayed by another year in a school type structured environment. Policies and practices that focus on leaving school may not therefore have the desired impact on health and wellbeing. In addition, weight gain prevention programmes need to be tailored to take account of this longer transition period in this population.

It is noteworthy that the majority (71%) of the participants in this study were male. This may have impacted the results, in terms of recruitment and retention rates and also study outcomes. Future research should try to recruit a more gender balanced population.

At last, it is important to take account of the increasing evidence for the effectiveness of self-monitoring of health behaviours using wearable technology for example, Fit Bit, apple watch; (Lewis, Lyons, Jarvis, & Baillargeon, 2015). The evidence suggests that existing approaches to self-monitoring are not accessible for all individuals with intellectual disabilities (Mitchell et al., 2016). However, it is possible to develop wearable technology tailored to the individual needs of adolescents with intellectual disabilities, that can be used for self-monitoring. Thus, technology which can assist with self- monitoring could play an influential role in changing the health behaviours in this population. To conclude, this work suggests that adolescence may be a high- risk period for weight gain in adolescents with intellectual disabilities. Larger scale studies, which track this transition over the longer term, are needed.

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