



## AN ABSTRACT OF THE DISSERTATION OF

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Activity Behavior in Adults with Intellectual Disabilities.

Abstract approved:

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The purpose of this study was to examine the evidence of construct validity for self-report with assistance from a secondary source as a measure of physical activity (PA) in adults with intellectual disabilities (ID) in free-living environments. Thirty-seven participants (21 females, 16 males) with mild to moderate ID aged 19-74 years participated in the study. The Multitrait-Multimethod (MTMM) analysis was used to evaluate the evidence of construct validity for this procedure. Examination of the pattern of reliability and validity coefficients of the MTMM analysis revealed that the reliability coefficients for the self-report variables (PA and fat intake), activity counts, and step counts were higher than all convergent validity coefficients, except for the convergent validity between the two objective measures of PA, and discriminant validity coefficients. The convergent validity coefficients were greater than all of the discriminant validity coefficients except for the heterotrait-monomethod discriminant validity coefficient. The heterotrait-monomethod discriminant validity coefficient was higher than the heterotrait-heteromethod discriminant validity coefficients. The study

demonstrated that self-report with assistance from a secondary source as a measure of PA in adults with ID has strong and generalized evidence of convergent validity and strong evidence of discriminant validity.

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Construct Validation of Self-Report with Assistance to Measure Physical  
Activity Behavior in Adults with Intellectual Disabilities

by

Marquell J. Johnson

A DISSERTATION

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Chair of the Department of Nutrition and Exercise Sciences

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Dean of the Graduate School

I understand that my dissertation will become part of the permanent collection of  
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Marquell J. Johnson, Author

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## CONTRIBUTION OF AUTHORS

Dr. Jeffrey McCubbin assisted in the writing of the manuscript. Dr. Joonkoo Yun assisted in the interpretation of the data and writing of the manuscript.

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# Construct Validation of Self-Report with Assistance to Measure Physical Activity Behavior in Adults with Intellectual Disabilities

## Chapter 1: Introduction

It is the consensus that physical activity (PA) is positively associated with health benefits and decreased risk in mortality and morbidity associated with many chronic diseases and conditions (Pate, Pratt, Blair, Haskell, et al., 1995; United States Department of Health and Human Services [USDHHS], 1996). Physical activity is a complex behavior that can be examined from multiple dimensions. Due to the complexity in PA behavior, a variety of measurement tools have been used to examine this behavior with each one having its own advantages and disadvantages. The ability to relate physical activity to health depends on accurate, precise, and reproducible measures. Accurate measurement of PA allows for the identification of individuals and/or groups that may be at risk of sedentary behavior and the associated health risks that accompany sedentary behavior. It is also used to evaluate the effectiveness of interventions developed to increase PA and better understand the mechanisms through which these benefits are conferred (USDHHS, 1996; Dishman, Washburn, & Schoeller, 2001).

In the general population, multiple national recommendations and initiatives on PA have been developed through the use of physical activity questionnaires. When epidemiological studies use subjective measures, such as questionnaires, an objective measure is often used to validate the activity measure. PA questionnaires with evidence of relative validity, shown by correlations with a known criterion, are useful in studies of associations with health outcomes and to assess outcomes in controlled

intervention studies (Sallis & Saelens, 2000). The reliability and validity of PA questionnaire outcomes are affected by one's ability to remember information which can lead to incomplete recall or exaggeration of amount of activity (USDHHS, 1996; Kriska & Casperson, 1997; Patterson, 2000; Shephard, 2003; Warm, 2006).

Reliability and validity of the data collected can also be influenced by multiple factors including interviewer or respondent bias, the day of the week being probed, and the sequence of administration of the questionnaire within the battery of other measures collected (USDHHS, 1996; Kriska & Casperson, 1997).

With the increased efforts to move adults with intellectual disabilities (ID) from institutional settings into the community, the need for surveillance and measurement of their physical activity behavior is an important health priority (Lakin, Hill, and Bruininks, 1988; Braddock, Hemp, Fujiura, Bachelder, and Mitchell, 1990; Chanias, Reid, & Hoover, 1998; USDHHS, 2002). For a majority of people with ID, their condition is relatively mild, and once they leave school, they are integrated into larger communities, untracked in major national data sets (USDHHS, 2002). Several reasons for the inactive lifestyle often found in persons with disabilities have been postulated. These include lack of knowledge concerning the importance of exercise to healthy living, limited access to transportation to and from the activity site, inaccessible facilities and equipment, and a perception by some individuals that they are not able to exercise as result of their disability (Rimmer, Braddock, & Pitetti, 1996). Other reasons include: less structure in community settings, which results in less programmed PA time than in other settings; adults with ID have large amounts of

leisure time; and adults with ID in the community choose to be inactive, which might not be a choice honored in other living environments (Frey, 2004).

There is a paucity of population-based information on the physical activity behavior of adults with ID living in the community (Rimmer, Braddock, & Pitetti, 1996; Stanish, Temple, & Frey, 2006; Temple, Frey, & Stanish, 2006). This issue was made evident in the Healthy People 2010 objectives for individuals with disabilities that identified a lack of available research with large representative samples of the population to develop adequate recommendation for individuals with disabilities (USDHHS, 2000). Of the studies published, a variety of methods have been used to determine PA levels of individuals with ID. These methods include objective measures such as pedometers, accelerometers, and observation systems and subjective methods based on PA questionnaires or interviews with people with ID or those who live or work with them (Temple & Walkley, 2003; Frey, 2004; Temple, Frey, & Stanish, 2006).

The use of questionnaires to capture the physical activity of adults with ID has been utilized most often (Beange, McElduff, & Baker, 1995; Messent, Cooke, & Long, 1998; Robertson, Emerson, Gregory, Hatton, et al., 2000; Draheim, Williams, & McCubbin, 2002; Temple & Walkley, 2003; Draheim, Williams, & McCubbin, 2003). Due to issues related to level of cognition and recall in this population, researchers have relied on the use of secondary sources to assist individuals with ID in their responses to questionnaires. However, the studies that have used questionnaires with individuals with ID have not provided evidence of validity for the questionnaire outcomes while using a secondary source.

The lack of evidence of validity for using self-report with assistance to measure the PA of individuals with ID casts doubt when comparing their results to those of the general population (Temple, Frey, & Stanish, 2006; Warm, 2006). Accurate measurement of PA is vital to obtain broad based valid data of PA levels among adults with ID and to be able to assess the efficacy and effectiveness of longitudinal interventions (Temple, Frey, & Stanish, 2006). Any decisions made about people based on data that lack validity are at best questionable and probably in error (Mahar & Rowe, 2002). Therefore, the purpose of this study was to examine the evidence of construct validity for self-report with assistance from a secondary source as a measure of physical activity in adults with intellectual disabilities (ID) in free-living environments.

### Research Questions

The following research questions were investigated in this study:

1. What is the construct-related evidence of validity for using self-report with assistance as a measure of physical activity in adults with ID?
2. How well does self-report with assistance from a secondary source correlate with other measures of physical activity in adults with ID?
3. How reliable are self-report with assistance, pedometers, and accelerometers in measuring physical activity in adults with ID?



## Assumptions

For conducting this study, the following assumptions were made:

1. Accelerometer and pedometer were accurately placed on participants during unobserved periods of data collection.
2. Accelerometer and pedometer were worn at all times during waking hours unless participant's were showering and/or swimming.
3. There were no changes in participant habitual physical activity from week 1 and week 2 of observation.

## Delimitations

The following aspects delimited the study:

1. This study was delimited to adults with ID aged 19 and older living in the community in a Pacific Northwest state.
2. This study was delimited to the PA measurement used in this study. The NHANES III Physical Activity Questionnaire was used to assess habitual physical activity behavior. Pedometers were used to measure the number of steps accumulated. Accelerometers were used to measure activity counts accumulated.
3. This study was delimited to the thirty-seven participants who volunteered for the study.

## Limitations

The following limitations affected the study:

1. Unequal distribution of participants living in different living arrangements in the community.
2. A higher proportion of adults with Down syndrome than what is generally observed in the U.S. population of adults with ID.

### Definitions

Physical Activity – any bodily movement produced by skeletal muscles that result in energy expenditure (Caspersen, Powell, & Christenson, 1985).

Validity – the appropriateness, meaningfulness, and usefulness of the specific inferences made from test scores (Standards for Educational and Psychological Testing, American Psychological Association, 1995, p. 9).

Physical Activity Bouts – any activity that participant's reported doing for a specified period of time that resulted in energy expenditure.

Group Home – Residential facilities in the community designed to provide 24-hour supervised care, training and support for individuals with developmental disabilities.

Group homes provide room and board as well as an array of services to residents.

Group homes can vary in the number of individuals who live there and the number of staff, depending on the support needs of the individuals. There is some group homes designed to serve individuals with complex medical needs, as well as those with

challenging behavioral needs (Oregon Department of Developmental Disabilities)

(<http://www.oregon.gov/DHS/dd/adults/residential.shtml#grouphomes>).

Semi-Independent - Residential support and skill training provided to persons living in their own home or apartment. The training and support is provided in such areas as managing money, planning meals, shopping and using community resources and recreation. These services vary in intensity, averaging approximately four (4) hours per week (Oregon Department of Developmental Disabilities)

(<http://www.oregon.gov/DHS/dd/adults/in-home.shtml#silp>).

## CHAPTER 2

Construct Validation of Self-Report with Assistance to Measure Physical  
Activity Behavior in Adults with Intellectual Disabilities

Marquell J. Johnson

## ABSTRACT

The purpose of this study was to examine the evidence of construct validity for self-report with assistance from a secondary source as a measure of physical activity (PA) in adults with intellectual disabilities (ID). Thirty-seven participants with mild to moderate ID participated in the study. The Multitrait-Multimethod (MTMM) analysis was used to evaluate the evidence of construct validity. Examination of the pattern of reliability and validity coefficients revealed that the reliability coefficients for the self-report variables (PA and fat intake), activity counts, and step counts were higher than all convergent validity coefficients, except for the convergent validity between the two objective measures of PA, and discriminant validity coefficients. The convergent validity coefficients were greater than all of the discriminant validity coefficients except for the heterotrait-monomethod discriminant validity coefficient. The heterotrait-monomethod discriminant validity coefficient was higher than the heterotrait-heteromethod discriminant validity coefficients. The study demonstrated that self-report with assistance from a secondary source as a measure of PA in adults with ID has strong evidence of convergent and discriminant validity.

## INTRODUCTION

It is the consensus that physical activity (PA) is positively associated with health benefits and decreased risk in mortality and morbidity associated with many chronic diseases and conditions (Pate, Pratt, Blair, Haskell, et al., 1995; United States Department of Health and Human Services [USDHHS], 1996). Physical activity is a complex behavior that can be examined from multiple dimensions. Accurate measurement of PA allows for the identification of individuals and/or groups that may be at risk of sedentary behavior and the associated health risks that accompany sedentary behavior. It is also used to evaluate the effectiveness of interventions developed to increase PA and better understand the mechanisms through which these benefits are conferred (USDHHS, 1996; Dishman, Washburn, & Schoeller, 2001).

Due to the complexity in PA behavior, a variety of measurement tools have been used to examine this behavior. Currently, self-report questionnaires, accelerometers, and pedometers are the most common and practical methods for assessing PA in both populations with and without disabilities with each one having its own advantages and disadvantages (Casperson, 1989; Warm, 2006; Temple, Frey, and Stanish, 2006). Despite the disadvantages of self-report instruments, they continue to be the most widely used type of PA measure because of their ability to collect data from a large number of people at low cost, they do not alter the behavior under study, and it is possible to assess all the dimensions of PA (Sallis & Saelens, 2000)

The need for surveillance and measurement of physical activity behavior in adults with intellectual disabilities (ID) living in the community has become an

important health priority (Lakin, Hill, and Bruininks, 1988; Braddock, Hemp, Fujiura, Bachelder, and Mitchell, 1990; Chanias, Reid, & Hoover, 1998; USDHHS, 2002). The use of self-report to capture the physical activity of adults with ID has been utilized in previous research (Beange, McElduff, & Baker, 1995; Messent, Cooke, & Long, 1998; Robertson, Emerson, Gregory, Hatton, et al., 2000; Draheim, Williams, & McCubbin, 2002; Temple & Walkley, 2003; Draheim, Williams, & McCubbin, 2003). Likely due to issues related to level of cognition in this population, researchers have relied on the use of secondary sources (i.e. family, group home staff, care providers) to assist individuals with ID in their responses to self-report PA questionnaires.

Studies that have used self-report with assistance from secondary sources to measure PA in individuals with ID have not examined the evidence of validity for using this approach. Accurate measurement of PA is vital to obtain broad based valid data of PA levels among adults with ID and to be able to assess the efficacy and effectiveness of longitudinal interventions (Temple, Frey, & Stanish, 2006). Any decisions made about people based on data that lack validity are at best questionable and probably in error (Mahar & Rowe, 2002). In other words, it is questionable if the research has captured the true PA behavior of adults with ID without adequate support of validity evidence (Finlay & Lyons, 2001; Temple & Walkley, 2003; Frey, 2004; Stanish, Temple, & Frey, 2006; Temple, Frey, & Stanish, 2006).

The Multitrait-Multimethod (MTMM) analysis is a statistical technique used to evaluate construct-related validity evidence of measurement (Campbell & Fiske, 1959). It is a systematic procedure for evaluating the strength and pattern of multiple

indices including (a) reliability coefficients, (b) convergent evidence (evidence that measures of the same construct correlate highly), and (c) discriminant evidence (evidence that measures of different constructs do not correlate as highly as measures of the same construct) (Campbell & Fiske, 1959). Considering the complex nature of PA, employing the MTMM appears to be promising in evaluating validity evidence of such a complex construct.

This study examined the evidence of construct validity for self-report with assistance from a secondary source to measure PA in adults with ID living in the community using MTMM analysis. We hypothesized that self-report with assistance from a secondary source to measure PA would correlate highly with objective measures of PA (accelerometers and pedometers), providing evidence of convergent validity. We hypothesized that a self-report with assistance measure of fat intake in adults with ID would not correlate as high with self-report with assistance to measure PA and objective measures of PA, providing evidence of discriminant validity. This study also examined the reliability of self-report with assistance, pedometers, and accelerometers in measuring PA in adults with ID.

## Method

### Participants

Thirty-seven participants (21 females, 16 males) with mild to moderate ID aged 19-74 years (females ages,  $M = 40.57 \pm 14.24$ ; males ages,  $M = 37.38 \pm 12.93$ ) participated in the study. Eleven of the participants had Down syndrome (7 females, 4 males). Down syndrome was the only specific etiology requested. Participants were recruited through county offices of Developmental Disabilities Services, area Arc



offices in a northwestern state, and private and state operated assisted living programs. Due to confidentiality policies of these service agencies, we were not allowed to recruit participants directly until the service agencies performed an initial screening of interested participants. Service agencies were asked to identify eligible participants based on the following criteria: (a) having an ID as defined by the American Association on Mental Retardation (Luckasson et al., 2002); (b) residence in a community setting; and (c) independent ambulation. The aforementioned organizations and agencies identified interested participants and forwarded their contact information to the first author. The living arrangements of the participants were distributed accordingly: Six (16%) participants lived with family; 21 (57%) lived in group homes; and 10 (27%) lived semi-independently.

Prior to the signing of the informed consent form, the investigators explained the procedures before obtaining the informed consent from the participants and/or their legal guardians. The consent form and all procedures were approved by a University Institutional Review Board for the Protection of Human Subjects. Participants and secondary sources were compensated for their time, effort, and contributions to the study with a \$20.00 and \$10.00 gift card respectively.

#### Demographic Data

Weight (kilograms) and height (cm) were measured with participants dressed in lightweight clothing. Body Mass Index (BMI) was calculated using weight and height measurements. Age, gender, ID condition (DS and non-DS), and weekly working hours were collected on all participants. Table 2.1 provides descriptive data

on the participants. Table 2.2 provides descriptive data on the secondary sources that assisted with self-report responses.

Table 2.1 Descriptive Data of Participants

	Females (n=21)	Males (n=16)	All Participants (n=37)
Age (years)	40.57 $\pm$ 14.24	37.38 $\pm$ 12.93	39.19 $\pm$ 13.59
Height (cm)	150.34 $\pm$ 14.71	164.25 $\pm$ 11.78	156.14 $\pm$ 15.09
Weight (kg)	70.60 $\pm$ 12.25	71.98 $\pm$ 16.41	71.20 $\pm$ 14
BMI (kg/m <sup>2</sup> ) <sup>1</sup>	31.26 $\pm$ 3.93	26.24 $\pm$ 6.25	29.17 $\pm$ 5.55
Working Hours <sup>2</sup>	18.70 $\pm$ 7.54	21.83 $\pm$ 6.60	19.88 $\pm$ 7.26
PA bouts <sup>3</sup>	13.36 $\pm$ 6.75	11.91 $\pm$ 4.08	12.73 $\pm$ 5.73
Activity Counts <sup>4</sup>	128962.24 $\pm$ 49269.98	131654.11 $\pm$ 69159.18	130126.30 $\pm$ 57821.88
Step Counts <sup>5</sup>	6809.63 $\pm$ 3056.20	6406.72 $\pm$ 3693.61	6635.40 $\pm$ 3303.72
Fat intake <sup>6</sup>	2.17 $\pm$ 0.66	2.59 $\pm$ .46	2.35 $\pm$ 0.61

Note: <sup>1</sup>Height and BMI variables exclude 1 participant for missing data. <sup>2</sup>Working

Hours are per week and exclude 5 participants because they did not work. <sup>3</sup>PA bouts are an average of bouts reported per interview. <sup>4</sup>Activity counts (accelerometer data) are a daily average of activity counts accumulated over 14 day observation. <sup>5</sup>Step counts are a daily average of steps accumulated over 14 day observation. <sup>6</sup>Fat intake is an average of intake reported per interview based on values (1=low, 2=normal, 3=high).

Table 2.2 Descriptive Data of Secondary Sources

Gender	23 (71.9%) Females	9 (28.1%) Males	
Age	42.06 ± 17.15 (yrs)		
Time Spent with Participant	50.28 ± 52.08 hrs/wk		
Relationship <sup>1</sup>	9 (28.1%) FM	10 (31.3%) CP	13 (40.6%) GHS
Living Arrangement <sup>2</sup>	7 (21.9%) LwP	25 (78.1%) DLwP	

Note: <sup>1</sup>GHS = Group Home Staff; <sup>1</sup>FM = Family Member; <sup>1</sup>CP = Care Provider; <sup>2</sup>LwP

= Lived with Participant; <sup>2</sup>DLwP = did not live with participant

### Physical Activity Behavior

The PA questionnaire section of the Third National Health and Nutrition Examination Survey (NHANES) III (National Center for Health Statistics, 1994) was used to assess regular PA habits (Please see appendix D for the complete NHANES III instrument). The PA survey was administered by the first author through an interview with the participant and the secondary source to assist with questions when needed.

Contents of the interviewer-administered survey on PA determined if participants had walked 1 mile or more at a time without stopping or jogged or runs; rode a bicycle; swam; participated in aerobics or aerobic dance; other dancing; calisthenics or floor exercise; gardening or yard work; or lifted weights during the past month (day and week). For each positive response, participants were asked how many times and how long they performed the activity. Participation rates of up to four other exercises, sports, or PA hobbies not previously listed were also recorded. The original mode of administration of the NHANES III PA survey is interviewer-administered and this has been shown to be the most suitable form of self-report for adults with ID (Finlay & Lyons, 2001).

Accelerometers and pedometers were used as objective measures of PA for the participants. The Actiwatch (Mini Mitter, Bend, OR) is a small, lightweight, limb or waist worn, activity monitoring device. The Actiwatch activity monitor contains an omni-directional sensor that is sensitive to motion in all directions. An increased degree of speed and motion produces an increase in voltage. The monitor stores these data as activity counts. Activity counts are calculated based on the sampling epoch, and the total number of activity counts is compared to the threshold sensitivity value selected by the researcher. A 30-second sampling epoch was used in this study.

Omron HJ-112 pedometers (Omron Healthcare, Vernon Hills, IL) were used to measure the number of steps that each participant accumulated. According to the manufacturer, this pedometer does not count steps until it has registered over four seconds of movement, which can eliminate the chance of counting non step movements as steps. It is also capable of counting steps correctly even when the front of the main unit is placed at an angle of more than 60 degrees from the ground as well as when it is horizontal to the ground. This feature may accurately measure steps of individuals with high waist circumference because this pedometer may be less susceptible to errors that occur due to tilt. The pedometer can store steps for seven days and has an internal clock that automatically resets the counts to zero, so users do not have to press the reset button every day. Pedometers were sealed to prevent tampering during wearing.

#### Dietary Fat Intake

The Block Fat Screener (NurtitionQuest, Berkeley, CA) was used to examine dietary fat intake. In order to complete evaluation of the MTMM analysis,

discriminant validity evidence is needed and the results from the dietary fat intake were used for evaluating evidence of discriminant validity. This brief screening tool includes 17 questions, and it is designed to rank individuals from low to high with regard to their usual fat intake during the week and/or month. The screener includes the top sources of fat as determined by national surveys and recent research (Block, Gillespie, Rosenbaum, & Jenson, 2000). For the purposes of analyses, a corresponding number from 1 to 3 was assigned to the low to high rankings, respectively. Fat intake served as the second trait (construct) that was used to examine the strength of validity evidence for self-reported PA with assistance from a secondary source in adults with ID.

#### Procedures

Participants wore an elastic belt consisting of an accelerometer and pedometer located on their right waist/hip during waking hours, except for when performing water activities, for two 7-day periods. Accelerometers were exchanged every 2-3 days depending on location of participant from the researcher and pedometers were unsealed during the exchange time to record previous step counts and check for potential tampering. Following the first 7 days of wearing the accelerometer and pedometer, The NHANES III PA survey and Block Fat Screener were administered to the participants with ID and secondary source. These procedures were repeated following the second 7 consecutive days of wearing the monitors. The time between first and second administration of the two self-report surveys was an average of 7 days with a range between 2 and 14 days.

#### Statistical Analysis

Descriptive statistics were used to summarize all demographic information and evidence of validity was evaluated using the MTMM analysis. The MTMM analysis is a systematic procedure for evaluating the evidence of validity of a measurement instrument by examining the pattern of multiple validity and reliability coefficients (Campbell & Fiske, 1959). It will examine the strength of the convergent evidence (evidence that measures of the same construct correlate highly), discriminant evidence (evidence that measures of different constructs do not correlate as highly as measures of the same construct) and reliability evidence. Reliability coefficients are also required for the MTMM analysis.

The MTMM analysis is evaluated by examining the pattern of multiple reliability and validity coefficients. The reliability coefficients should be greater than the convergent and discriminant validity coefficients. The reliability coefficients represent the agreement between two efforts to measure the same construct using the same methods and therefore should be higher than the convergent validity coefficients which use dissimilar methods to measure the same construct and the discriminant validity coefficients which is measuring a different construct and using both similar/dissimilar methods. The convergent validity coefficients should be greater than discriminant validity coefficients. The convergent validity coefficients represent the agreement between two attempts to measure the same construct through different methods and therefore should be higher than the discriminant validity coefficients which represent the relationship between different constructs utilizing similar and dissimilar methods of measurement. Also, among discriminant validity coefficients, coefficients from heterotrait-monomethod (relationship between self-reported PA and

fat intake) should be higher than coefficients from heterotrait-heteromethod (relationship between self-reported fat intake and objective measures of PA) (Campbell & Fiske, 1959; Yun & Ulrich, 2002). When the expected pattern of reliability and validity coefficients is apparent, the evidence of construct validity becomes stronger. Because the researchers were only interested in establishing evidence of construct validity for the PA measure, a convergent validity coefficient for fat intake was not included.

Reliability coefficients were calculated from a two-way random intraclass correlation to examine interview-1 to interview-2 reliability in self-reported PA bouts and fat intake, total number of activity counts per 7-day observation, and total number of steps taken per 7-day observation. Pearson-Product Moment correlation coefficients were calculated to examine the association between self-reports with assistance variables (reported PA bouts per interview and reported fat intake per interview), accelerometers, and pedometers. Analyses were performed using SPSS 15.0 (Statistical Package for the Social Sciences, Inc, Chicago, IL).

## Results

Mean and standard deviations for the variables used in this study are provided in Table 2.1. Examination of the pattern of reliability and validity coefficients of the MTMM analysis revealed the expected outcome. Reliability coefficients were the highest followed by the convergent validity coefficients and discriminant validity coefficients. Reliability coefficients, convergent validity coefficients, and discriminant validity coefficients are included in Figure 1. The range of the reliability coefficients was  $ICC(2, 2) = 0.78$  to  $ICC(2, 2) = 0.96$ . The reliability coefficient for self-report

with assistance as a measure of PA was ICC (2, 2) = 0.80. According to guidelines provided by Cohen (1988), the magnitude of this reliability coefficient is high. As expected, the reliability coefficients from the two objective measurements of PA (accelerometers and pedometers) were higher than the subjective measurements. The results indicated that self-report with assistance as a measure of fat intake had the lowest reliability coefficient.

Figure 1. Multitrait-Multimethod Matrix

	<b>Self-Report</b>		<b>Objective Measure</b>	
	PA	Fat Intake	Accelerometers	Pedometers
<b>Self-Report</b>				
PA	<b>.80</b>			
Fat Intake	-.37*	<b>.78</b>		
<b>Objective Measure</b>				
Accelerometers	<u>.34*</u>	.00	<b>.91</b>	
Pedometers	<u>.52**</u>	-.23	<u>.85**</u>	<b>.96</b>

Note: Reliability coefficients are in bold print; convergent validity coefficient (monotrait-heteromethod/monomethod) are underlined; discriminant validity coefficient 1 (heterotrait-monomethod) is italicized; discriminant validity coefficient 2 (heterotrait-heteromethod) are in normal text. \* Correlation is significant at the 0.05 level. \*\* Correlation is significant at the 0.01 level.

The convergent validity coefficients for self-reported PA, accelerometers, and pedometers were  $r = 0.34$  ( $p \leq 0.05$ ) and  $r = 0.52$  ( $p \leq 0.01$ ), respectively. Convergent validity coefficient between the objective measures of PA was  $r = 0.85$  ( $p \leq 0.01$ ).



The expected coefficient from objective measures of PA should be higher than correlations between self-reported PA and objective measures of PA because the correlation between the objective measures is considered monotrait-monomethod whereas correlation between the subjective measure and objective measures are considered monotrait-heteromethod.

The discriminant validity coefficients between self-reported fat intake and PA was  $r = -0.37$  ( $p \leq 0.05$ ). The discriminant validity coefficients between self-reported fat intake and the objective measures of PA (accelerometers and pedometers) were  $r = 0.00$  and  $r = -0.23$ , respectively.

### Discussion

The primary goal of this study was to examine the evidence of construct validity for self-report with assistance from a secondary source as a measure of PA in adults with ID. Examination of the pattern of reliability and validity coefficients of the MTMM analysis reveals strong evidence of validity for PA assessment using self-report with assistance in adults with ID. The results of the reliability coefficients for the variables of self-report of PA, self-report of fat intake, activity counts, and step counts were higher than all convergent validity coefficients, except for the convergent validity between the two objective measures of PA, and discriminant validity coefficients. This reliability pattern could be viewed as a lack of validity evidence for self-report with assistance as a measure of PA. It was somewhat of an expected outcome. Previous researchers have reported higher evidence of validity and reliability for PA from objective measurement tools (Bassett, Cureton, & Ainsworth, 2000; Sallis & Saelens, 2000; Tudor-Locke, Ainsworth, Thompson, & Matthews,

2002; Tudor-Locke, Williams, Reis, & Pluto, 2002; Macfarlane, Lee, Ho, Chan, & Chan, 2006). The results from this study support the argument that objective measurements have better psychometric properties than subjective measurement tools. However, the validity evidence for self-report with assistance should not be overlooked. The low and moderate relationship between the self-report with assistance measure of PA and objective measures of PA is evidence for the measure's convergent validity. The convergent validity coefficients are greater than all of the discriminant validity coefficients except for the heterotrait-monomethod discriminant validity coefficient ( $r = -0.37, p \leq 0.05$ ). According to Campbell and Fiske (1959), this pattern is a typical occurrence when utilizing the MTMM analysis. It is explained that for any given measuring device, there are certain features introduced specifically to represent the trait (construct) it is intended to measure and there are other features which are characteristics of the method being employed, features which could also be present in efforts to measure other quite different traits.

The heterotrait-monomethod discriminant validity coefficient was higher than the heterotrait-heteromethod discriminant validity coefficients. The results demonstrate that the self-report with assistance measures of PA and fat intake were significantly correlated. This low relationship between the two self-report with assistance measures of PA and fat intake is evidence for the measure's discriminant validity (heterotrait-monomethod). There was also little to no correlation between the self-report with assistance measure of fat intake and objective measures of PA. The lack of relationship between the self-report with assistance measure of fat intake and

objective measures of PA is evidence for the measure's discriminant validity (heterotrait-heteromethod).

The study demonstrates that self-report with assistance from a secondary source as a measure of PA in adults with ID has strong and generalized evidence of convergent validity and strong evidence of discriminant validity. The strong evidence of convergent validity is supported from outcomes previously reported by Draheim, Williams, and McCubbin (2003) who demonstrated a strong association between self-reported PA with assistance via the NHANES III survey and certain cardiovascular disease risk factors. The strong evidence of convergent validity is further supported from previous studies that have indicated similar convergent validity coefficients between self-report measures of PA, accelerometers, and pedometers with individuals without disability (Bassett, Cureton, & Ainsworth, 2000; Sallis & Saelens, 2000; Tudor-Locke, Ainsworth, Thompson, & Matthews, 2002; Tudor-Locke, Williams, Reis, & Pluto, 2002; Le Masurier, Lee, & Tudor-Locke, 2004; Macfarlane, Lee, Ho, Chan, & Chan, 2006). The strong evidence of discriminant validity is supported from outcomes previously reported that indicated that PA was not significantly associated with BMI (Fujiura, Fitzsimons, Marks, & Chicoine, 1997) or abdominal obesity (Draheim, Williams, & McCubbin, 2002a) in adults with ID. Conversely, dietary fat intake was associated with abdominal obesity in adults with ID (Draheim, Williams, & McCubbin, 2002a).

Multiple studies (Beange, McElduff, & Baker, 1995; Messent, Cooke, & Long, 1998; Robertson, Emerson, Gregory, Hatton, et al., 2000; Draheim, Williams, & McCubbin, 2002b; Temple & Walkley, 2003; Draheim, Williams, & McCubbin,

2003) have used a form of self-report with assistance from a secondary source as a measure of PA in adults with ID but have failed to include any information regarding the reliability of this procedure and have provided little to no evidence of validity for this procedure. This study provides further evidence that self-report with assistance from a secondary source as a measure of PA via the NHANES III survey is a reliable procedure to use with adults with ID. Our self-report with assistance measure of PA reliability coefficient was similar to the value previously reported by Stanish and Draheim (2005). The authors performed a reliability study with a subset of their experimental group ( $N = 12$ ) and found that for total number of PA bouts per week and total minutes of PA per week self-reported with assistance via the NHANES III survey was reliable ( $r = 0.87$  and  $r = 0.89$ , respectively). The reliability coefficients of our study are also similar to reported values of self-reports measures used to measure PA in adults without disabilities (Jacobs, Ainsworth, Hartman, & Leon, 1993).

This study provides further evidence that pedometer outcomes are a reliable measure of PA in individuals with ID. Our pedometer reliability coefficient value was similar to values previously reported by Stanish (2004) who examined the accuracy of pedometers and walking activity in adults with ID. The author found that all coefficient values were  $\geq$  ICC 0.95. This study also provides evidence that accelerometer outcomes are a reliable measure of PA in adults with MR. Our accelerometer reliability value was higher than the value (ICC = 0.87) previously reported by Frey (2004) who compared PA levels between adults with and without MR. The reported ICC value was indicative of reliability across days (5 days) unlike this study that examined reliability across weeks (14 days).

Our study was the first to demonstrate a significant relationship among self-report with assistance from a secondary source via the NHANES III PA survey and pedometer outcomes. A previous study by Stanish and Draheim (2005) that assessed walking activity using a pedometer and the NHANES III PA survey in adults with MR found no significant correlations between pedometer step counts and any of the NHANES III PA survey variables (including total number of PA bouts per week reported). One reason for the different outcomes from the two studies may include the duration of observation (7 days vs. 14 days). The previous study also only considered MVPA bouts as defined by Ainsworth Compendium of PA (Ainsworth et al., 1993), unlike the present study that considered all PA bouts reported. The previous study could not account for device tampering because pedometers needed to be reset every morning by participant and/or caregiver. In our study, pedometers were sealed and were capable of storing steps for seven days and automatically resetting which controlled for device tampering. The population sample differed between the two studies in size, location, and composition. Lastly, the type of pedometers used in the studies was different. Previous studies have found that pedometers from different manufacturers will produce different measurement outcomes (Crouter, Schneider, Karabulut, & Bassett, 2003; Schneider, Crouter, & Bassett, 2004; Crouter, Schneider, & Bassett, 2005).

To our knowledge, this study was the first to demonstrate a significant relationship among self-report with assistance from a secondary source via the NHANES III PA survey and accelerometer outcomes. Two previous studies by Temple and colleagues (Temple, Anderson, & Walkley, 2000; Temple and Walkley,

2003) examined the relationship between direct observation of PA and PA measured via accelerometer in adults with ID and the relationship of 3-day caregiver diary of PA and PA measured via accelerometer. The authors reported intraclass correlation coefficients of 0.83 and 0.78, respectively. Our study was also the first to demonstrate a significantly high relationship between accelerometer (total number of activity counts per week) and pedometer (total number of step counts per week) outcomes as measures of PA in adults with ID ( $r = 0.85$ ,  $p = 0.01$ ). As stated previously in the discussion regarding convergent validity, this finding was similar to results found in studies that examined this relationship in individuals without disabilities.

Previous studies (Draheim, Williams, & McCubbin, 2002b; 2003; Stanish & Draheim, 2005) that have used self-report with assistance as a measure of PA in adults with ID have rationalized its use based on two assertions. Adults with ID residing in the community routinely participate in certain physical activity on daily and weekly basis. Secondary sources that assist with self-report measures are more likely to assist with the daily activity schedules of the adults with ID and are therefore knowledgeable of their habitual PA behaviors. However, these studies provide no support for these assertions. In this study, 24 (75%) of the secondary sources spent  $\geq 20$  hours and  $\geq 3$  days a week with the participant they assisted. Twenty-eight (88%) of the secondary sources that assisted with self-report measures assisted for both administration of the measures. It is likely that these factors contributed to the findings of this study.

The MTMM approach used in this study to provide evidence of construct validity for self-report with assistance from a secondary source as a measure of PA in

adults with ID evaluates the relationships between and within constructs (PA vs. fat intake). The MTMM approach allows for the collection of comprehensive evidence to validate the adequacy and appropriateness of decisions made from measurement outcomes. This approach afforded the researchers an opportunity to utilize multiple measures (self-report, accelerometers, and pedometers) to examine the PA behaviors of adults with ID. The utilization of multiple measures to examine PA has been a point of emphasis in terms of improving the quality of PA research with disability populations (Yun and Ulrich, 2002; Temple, Frey, and Stanish, 2006; Warm's, 2006). The NHANES III PA survey was used as the self-report measure in this study and the results indicate that this instrument when used with a secondary source can be used to capture the PA habits in adults with ID. This may allow or improve the ability of researchers to make comparisons between the respective groups' data. This is the first study to our knowledge to have a collection period a minimum of 14 days for accelerometer and pedometer data. The extended period of time for collection coupled with the high reliability and validity coefficients provides evidence that more longitudinal studies of PA behavior in adults with ID can be undertaken. Lastly, this study provided detailed demographic data on both participants with ID and the secondary sources that assisted them with self-report responses. None of the previous studies that have utilized self-report with assistance as a measure of PA in adults with ID have provided such descriptions on secondary sources.

Limitations of this study include all of the following. The participants were not randomly selected, but volunteered. The sample of the present study included a higher proportion of adults with Down syndrome than what is generally observed in

the U.S. population of adults with ID. However, no statistical significance was found when the researchers examined group differences on all variables of interest (self-report variables, activity counts, & step counts). The data were collected during the summer months, when PA habits likely differ from those occurring during colder and inclement seasons. Seasonal variation in participation may influence the estimates of prevalence of PA via questionnaires (USDHHS, 1996; Draheim, Williams, and McCubbin, 2002b; 2003; Temple, Frey, and Stanish, 2006).



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## CHAPTER 3: CONCLUSIONS

Reliability and validity issues of individuals with ID responses to self-report measures of PA with assistance from a secondary source have been identified as a pressing research need in the literature (Draheim, Williams, and McCubbin, 2002; 2003; Temple, Frey, and Stanish, 2006). The purpose of this study was to examine the evidence of construct validity for self-report with assistance from a secondary source as a measure of PA in adults with ID. The MTMM analysis was used to examine the evidence of construct validity for this procedure. The study demonstrated that self-report with assistance from a secondary source as a measure of PA in adults with ID has strong and generalized evidence of convergent validity and strong evidence of discriminant validity. The outcomes from this study provide good evidence of construct validity for self-report with assistance from a secondary source as a measure of PA in adults with ID. Results also indicated that accelerometer and pedometer outcomes are reliable and that significant relationships exist among the outcomes as measures of PA in adults with ID.

Future studies examining the evidence of construct validity for self-report with assistance as a measure of PA with adults with ID should consider using different self-report measures of PA. Researchers should continue examining the construct validity of self-report with assistance as a measure of PA by examining relationships with pedometers and accelerometers from other manufacturers and by examining relationships with other measures of PA (i.e. physiological factors, psycho-social factors, disease risk factors). Researchers should systematically identify which items

on a questionnaire required assistance from secondary sources. Researchers should discover ways to measure the degree of assistance from a secondary source (i.e. videotaping interview, direct observation from a third person). In doing so, researchers would be able to identify certain items of a self-report measure or interviewing technique that may or may not be suitable for this population. This information could lead to the development of more suitable self-report measures and interview techniques for this population. Researchers should gather descriptive data on the secondary sources that are being used to assist adults with ID with self-report measures. This data could potentially include their education level completed, PA behaviors, and feelings towards the individual and job. This information would provide researcher with insight into how certain factors influence individuals with ID self-report responses.

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## APPENDICES

## APPENDIX A – REVIEW OF LITERATURE

### **Physical Activity and Health in the General Population**

It is the consensus that physical activity (PA) is positively associated with health benefits and can decrease risk in mortality and morbidity associated with many chronic diseases and conditions. Increased levels of regular PA are associated with lower mortality rates for both older and younger adults (Pate, Pratt, Blair, Haskell, et al., 1995; United States Department of Health and Human Services [USDHHS], 1996). Cardiovascular diseases (CVDs) which include coronary heart disease (CHD) and stroke have been shown to be related to low levels of PA and/or cardio respiratory fitness (USDHHS, 1996). Increased PA levels have been associated with an increase in high-density lipoprotein (HDL), which helps to protect against atherosclerosis. Increased PA also increases lipoprotein lipase activity and reduces levels of triglycerides in the blood. PA has also been shown to prevent or delay the development of high blood pressure as well as reduce blood pressure in people with hypertension. PA reduces thrombosis and has a protective effect against the risk of developing colon cancer. PA may prevent or delay the onset of Type II diabetes or reduce the likelihood of developing Type II diabetes altogether (USDHHS, 1996).

Obesity, which is considered to be at epidemic proportions in our society by some and considered to be a major public health problem in the U.S. by others, plays a central role in the development of diabetes mellitus and confers an increased risk for CHD, high blood pressure, osteoarthritis, dyslipoproteinemia, various cancers, and all-cause mortality (USDHHS, 1996). Obesity has been suggested to be an important

variable that may influence PA or sedentary behaviors (Epstein, 1998). Increased levels of PA are believed to prevent the likelihood of gaining weight over time and reducing the prevalence of obesity. Studies have shown lower weight, BMI, and skinfold measures among people with higher levels of self-reported PA or fitness (USDHHS, 1996; Pate et al., 1995).

PA is a complex behavior that can be examined from multiple dimensions. Due to the complexity in PA behavior, a variety of measurement tools have been used to examine PA behavior with each one having its own advantages and disadvantages in measuring PA. Some of the measurement tools used in PA research include calorimetry, job classification, survey procedures, physiological markers, behavioral observation, heart rate monitoring, and motion sensors (LaPorte, Montoye, & Casperson, 1985; Dishman, Washburn, & Schoeller, 2001). These tools vary considerably in the age groups which they can be applied, as well as in their cost, in their likelihood of affecting the behavior they try to measure, and in their acceptability (LaPorte, Montoye, & Casperson, 1985; USDHHS, 1996; Dishman, Washburn, & Schoeller, 2001). Currently, self-report surveys, accelerometers, and pedometers are the most common and practical methods for assessing PA (Casperson, 1989; Welk, 2002; Warm, 2006).

The ability to relate PA to health depends on accurate, precise, and reproducible measures. Accurate measurement of PA allows for the identification of individuals and/or groups that may be at risk of sedentary behavior and the associated health risks that accompany sedentary behavior. It is also used to evaluate the effectiveness of interventions developed to increase PA and to better understand the



mechanisms through which these benefits are conferred (USDHHS, 1996; Welk, 2002). An underlying measurement challenge within the PA epidemiology field is the need for valid and reliable measures of PA (Casperson, 1989; Dishman, Washburn, & Schoeller, 2001). One of the principle difficulties in establishing the validity of a PA measure is the lack of a suitable criterion measure for comparison (USDHHS, 1996; Morrow 2002). The most common methodological approach for research on assessments of PA has been to compare the convergent validity of the various techniques in assessing the same activity patterns (Dale, Welk, & Matthews, 2002). Direct observations, electronic surveillance, calorimetry, and HR monitors are often considered criterion measures in PA assessment but because these are difficult to obtain, surrogate measures such as self-report and logs have been used to estimate PA (Kriska & Casperson, 1997; Patterson, 2000; Morrow, 2002).

In the general population, many types of national recommendations and initiatives on PA have been gathered through the use of PA questionnaires. When epidemiological studies use subjective measures, such as questionnaires, an objective measure is often used to validate the activity measure. PA questionnaires with evidence of relative validity, shown by correlations with criteria, are useful in studies of associations with health outcomes and to assess outcomes in controlled intervention studies (Sallis & Saelens, 2000). PA questionnaires are typically chosen for population-based studies because they possess the characteristics of non-reactiveness (it does not alter the behavior of the individual being surveyed), practicality (there are reasonable study cost and participant convenience), applicability (the instrument can be designed to suit the particular population in question), and accuracy (has been

shown to be reliable and valid) (USDHHS, 1996; Kriska & Casperson, 1997; Sallis & Saelens, 2000). The questionnaire may be the only feasible method of assessing habitual PA in large populations (USDHHS, 1996; Shephard, 2003).

However, the reliability and validity of PA questionnaires are affected by one's ability to store and retrieve information which can lead to incomplete recall or exaggeration of amount of activity (USDHHS, 1996; Kriska & Casperson, 1997; Patterson, 2000; Shephard, 2003; Warm, 2006). Reliability and validity of the data collected can also be influenced by interviewer or respondent bias, the day of the week being probed, and the sequence of administration of the questionnaire within the battery of other measures collected (USDHHS, 1996; Kriska & Casperson, 1997; Sallis & Saelens, 2000).

Validity is considered to be the most important concept in measurement. Validity is defined as the "appropriateness, meaningfulness, and usefulness of the specific inferences made from test scores" (Standards for Educational and Psychological Testing, American Psychological Association, 1985). The inferences regarding specific uses of the test are validated, not the test itself. The ideal validation includes several types of evidence, which span all three of the traditional categories (content-related, criterion-related, and construct-related) (Messick, 1988). The unified concept of validity posits that construct validity is the only category of validity and that it subsumes content relevance and representativeness as well as criterion-relatedness (Messick, 1995). In construct validation, the test score is viewed as just one of an extensible set of indicators of the construct (Messick, 1995). Both convergent and discriminant evidence of validity are basic to construct validation

(Campbell & Fiske, 1959; Messick, 1995). Convergent empirical relationships reflecting communality among the set of indicators are taken to imply the operation of the construct to the degree that discriminant evidence discounts the intrusion of alternative constructs as plausible rival hypotheses (Campbell & Fiske, 1959; Messick, 1995). According to Messick (1995), when examining evidence of validity, one should not configure validity evidence that forestalls undue reliance on selected forms of evidence (traditional view) as opposed to a pattern of supplementary evidence, that highlights the important yet subsidiary role of specific content- and criterion-related evidence in support of construct validity in testing applications.

### **Physical Activity and Health in Adults with Intellectual Disabilities**

As a result of deinstitutionalization which began in the early 1970s, there has been a major effort in the U.S. and elsewhere to move people with intellectual disabilities (ID) out of institutions and into the community (Lakin, Hill, and Bruininks, 1988; Braddock, Hemp, Fujiura, et al., 1990; Chanas, Reid, & Hoover, 1998). The fiscal impact of this relocation has been substantial: state and federal commitments to support these individuals in the community have increased from \$900 million in 1977 to nearly \$10 billion in 1992 (Braddock, Hemp, & Fujiura, 1994). The question of how this movement into the community will impact the health status and PA behavior of adults with ID should be closely examined (Pitetti, Rimmer, & Fernhall, 1993; Rimmer, Braddock, & Fujiura, 1993; Rimmer, Braddock, & Marks, 1995). For a majority of people with ID, their condition is relatively mild, and once they leave school, they are integrated into larger communities, untracked in major national data sets (USDHHS, 2002). Less direct supervision of individuals with ID living in the

community has likely allowed for more personal choice of whether to participate in regular PA (Draheim, Williams, McCubbin, 2002). There are no data regarding the costs of inactivity in people with ID, but the lifetime direct medical and non-medical cost associated with this condition are estimated at over \$12 million (Honeycutt, Dunlap, Chen, Homsy et al., 2004). Indirect costs such as premature death, lost wages, and work limitations are estimated at over \$38 million and account for 76% of the total lifetime costs related to the ID diagnosis (Honeycutt et al., 2004).

The health status and PA behavior of adults with ID living in the community began to garner more attention beginning in the 1990's. If health is compromised due to inactivity, then independence will be limited. Essentially the ability of people with ID to exercise self-determination as integrated and productive members of society is influenced by their health, which is directly related to participation in regular PA (Stanish, Temple, & Frey, 2006). It is questionable whether individuals with ID are aware of the deleterious effects of a sedentary lifestyle. However, even if they were cognizant that inactivity may be harmful to their health, it is doubtful that they would have enough self-direction to alter their lifestyle (Pitetti, Rimmer, & Fernhall, 1993). An even more direct effort to reduce the health disparities among individuals with ID are outlined in the document *Closing the Gap*, which is a national blueprint derived from the U.S. Surgeon General's 2001 conference on health disparities and ID (USDHHS, 2002; Temple, Frey, & Stanish, 2006). Adults with ID represent a disability group who fit into the low education, low income, and blue-collar employment category and are likely to be physically inactive (Draheim, Williams, & McCubbin, 2002).

Several reasons for the inactive lifestyle often found in persons with disabilities have been postulated. These include lack of knowledge concerning the importance of exercise to healthy living, limited access to transportation to and from the activity site, inaccessible facilities and equipment, and a perception by some individuals that they are not able to exercise as result of their disability (Rimmer, Braddock, & Pitetti, 1996). For individuals with ID, other reasons include: less structure in community settings, which results in less programmed PA time than in other settings; adults with ID have large amounts of leisure time; and adults with ID in the community choose to be inactive, which might not be a choice honored in other living environments (Frey, 2004).

#### *Health Issues of Adults with Intellectual Disabilities*

Available literature on the health status of adults with ID living in the community has shown that obesity is a major health threat in persons with ID. Data indicates that the obesity levels of adults with ID are either similar to or higher than those in the general population (Rimmer & Yamaki, 2006). Americans with ID have a greater prevalence of obesity and extreme obesity compared to the general population (Pitetti, Rimmer, & Fernhall, 1993; Draheim, 2006; Rimmer & Yamaki, 2006). Obesity in this population has the potential to reduce or limit opportunities for various types of community participation, including employment and leisure, and can also require greater effort on the part of the caregiver in assisting the individual with ID with various activities and instrumental activities of daily living (Rimmer & Yamaki, 2006). Efforts to reduce obesity among adults with ID should be given one of the highest research and service priorities because of its strong association with various

health complications (e.g., hypertension, CHD, type 2 diabetes), reduced quality of life (QOL), and higher rates of mortality (Rimmer, Braddock, & Marks, 1995; Draheim, 2006; Rimmer & Yamaki, 2006).

Similar to the general population, CVD is the leading cause of death for persons with ID. Recent reports indicate that CVD-related deaths are greater for persons with ID than for the general population (Pitetti & Campbell, 1991; Pitetti, Rimmer, & Fernhall, 1993; Draheim, 2006). The subgroup of adults with mild to moderate ID who reside in community settings has been identified as possessing the greatest risk for CVD and possessing the most elevated CVD risk factors (Draheim, 2006). The physiological risk factors for CVD that have been reported include cholesterol profiles, hypertension, and overweight and obesity (Pitetti & Campbell, 1991; Rimmer, Braddock, & Fujiura, 1993; Rimmer, Braddock, & Marks, 1995; Draheim, Williams, & McCubbin, 2003; Draheim, 2006). The high prevalence of CVD risk factors indicates that, overall, adults with ID residing in community settings tend to have an elevated risk for a future CVD event (Draheim, 2006). The elevated CVD risk factors of adults with ID residing in community settings are likely due to elevated behavioral risk factors, such as low PA levels, high dietary fat intake, and low fruit and vegetable intake, which may potentially be modified to decrease the overall risk for CVD (Draheim, McCubbin, & Williams, 2003; Braunschweig, Gomez, Sheean, Tomey, et al., 2004; Draheim, 2006).

Available literature that has examined the nutritional status of adults with ID have found that their dietary intakes were poor or worse than that for the general U.S. population (Draheim, Williams, & McCubbin, 2003; Braunschweig et al., 2004;

American Dietetic Association [ADA], 2004). Bechtel and Schreck (2003) found adults with ID residing in group homes food intakes to be least closely related to the recommended dietary allowance (RDA), but with more calories and poorer food choices, when compared to adults without disabilities. Studies have shown that adults with ID do not report intakes of 5 or more servings of fruits and vegetables per day (Draheim, McCubbin, & Williams, 2003; Braunschweig et al., 2004; Draheim, 2006). Sodium intake was found to be 30% greater than the goal of 2400 mg/day or less, and fiber intake was found to be 28% less than the American Cancer Association recommendations of 25 g/day for this population (Braunschweig et al., 2004). When comparing fat intake among individuals with ID, physical disabilities, and those without disabilities, it has been shown that fat intake is greater in adults with ID (Draheim, McCubbin, & Williams, 2003; Bertoli, Battezzati, Merati, Margonato, et al., 2006).

#### *Physical Activity of Adults with Intellectual Disabilities*

Leisure time pursuits of individuals with ID living in the community tend to consist of sedentary behaviors. Temple, Anderson, and Walkley (2000) indicated that when adults with ID were asked to nominate the leisure activities that were enjoyed or participated in the most, they indicated activities such as listening to music and watching TV, knitting, meeting people, working on a computer, going to movies, and taking afternoon naps or resting. Hawkins (1993) reported on the leisure time pursuits of aging adults with ID and also on those activities that aging adults with ID preferred to increase participation in. The findings were similar to Temple, Anderson, and Walkley (2000), but also included such activities as eating out, shopping, and light

walking. Activities that aging adults with ID wanted to increase included going out to eat more and socializing with friends via visiting or calling. The omission of any type of moderate-to-vigorous PA as a leisure time pursuit observed in aging adults with ID indicates that these individuals will be faced with increased health risk as they age due to continued sedentary behavior.

There is a paucity of population-based information on the physical activity behavior of adults with ID living in the community (Rimmer, Braddock, & Pitetti, 1996; Stanish, Temple, & Frey, 2006; Temple, Frey, & Stanish, 2006). This issue was made evident in the Healthy People 2010 objectives for individuals with disabilities that identified a lack of available research with large representative samples of the population to develop adequate recommendation for individuals with disabilities (USDHHS, 2000). Of the studies published, a variety of methods have been used to determine PA levels of individuals with ID. These methods include direct measures such as pedometers, accelerometers, and observation systems and indirect methods based on PA questionnaires or interviews with people with ID or those who live or work with them (Temple & Walkley, 2003; Frey, 2004; Temple, Frey, & Stanish, 2006).

Beange, McElduff, and Baker (1995) examined the frequency of medical disorders in people with ID. As part of the survey that was administered, participants and their caregivers were asked whether the participants had engaged in vigorous exercise, defined as exercise “which made them breathe harder or puff and pant” in the past 2 weeks. The results indicated that adults with ID exercised less often and slept more than did people in the local population. The authors concluded that a serious



effort should be made to provide health promotion for adults with ID. The authors did not provide any evidence of validity for using the question pertaining to vigorous exercise for this population nor did they provide evidence of validity for self-report with assistance.

Draheim, Williams, and McCubbin (2002) used the NHANES III PA questionnaire to examine the prevalence of physical inactivity and recommended PA in community-based adults with ID. The questionnaire was administered to the individuals with ID with the assistance of their respective care providers in an interview format. The results of this study indicated that the prevalence of inactivity was high for both men and women with ID and that the prevalence for no leisure-time PA and little to no leisure-time PA for this group was similar to that reported for men and women in the general population. The authors did not provide any evidence of validity for using the NHANES III PA questionnaire with this population nor did they provide any evidence of validity or reliability for using self-report with assistance from a secondary source.

Messent, Cookes, and Long (1998) used the Allied Dunbar National Fitness Survey to examine the PA behavior of adults with learning disabilities and compared their PA behavior to those in the general population. In England, the term learning disabilities is synonymous to ID. The participants with learning disabilities were administered the questionnaire through an interview and their responses were later confirmed by day and residential care providers. The authors stated that these procedures suggested the respondents' recall to be accurate over a 7 day period. The authors concluded that the adults with learning disabilities PA profile suggest they

lead predominantly sedentary lifestyles which are more exaggerated than the sedentary lifestyles of the general population. The authors did not provide any evidence of validity for using the Allied Dunbar National Fitness Survey with this population and did not provide any evidence of validity or reliability for using secondary sources to confirm self-report responses of adults with ID.

Robertson, Emerson, Gregory, Hatton, et al. (2000) examined the lifestyle related risk factors for poor health in adults with ID living in England. As part of the study, the authors used items from the Health Survey for England to collect information on the participant's physical activity from the previous month. In this study, support team members that worked closely with the participants with ID were used to answer questions on the survey about their physical activity behaviors. Results from the study indicated that men and women with ID living in various settings were significantly more likely to lead inactive lifestyles than men and women without disabilities living in England. The authors did not provide any evidence of validity for using items from the Health Survey for England with this population and did not provide any evidence of validity or reliability for using secondary sources to obtain physical activity behavior information on adults with ID they work with.

Frey (2004) examined the PA levels of adults with ID compared to those in the general population (sedentary and active control groups) using accelerometers. The results indicated that the active control group was more active than adults with ID and sedentary controls during the assessment period. Also, there were no differences between adults with ID and sedentary controls on the PA measurement. The author

provided evidence of reliability ( $ICC = 0.87$ ) for accelerometer data across 5 days in adults with ID.

Temple, Andersen, and Walkley (2000) examined to what extent six individuals with ID living in a group home met the National Physical Activity Guidelines for Australians and how moderate-intensity PA was accrued by each person. Direct observation and accelerometers were used for data collection. Results indicated that participants spent approximately 10 hours per day lying down, 3 hours per day was spent in light activities while standing (bathing, shaving, cooking), 3 hours per day was spent in activities such as getting dressed/undressed or strolling, and grossly 6 hours per day were spent sitting involved in activities such as eating or watching TV. Results also indicated a high degree of convergent validity ( $ICC = 0.83$ ) between the two estimates of energy expenditure (direct observation vs. accelerometers). The author concluded that some individuals within this group of adults with ID accumulated sufficient moderate-intensity PA to meet the National Guidelines for PA involvement and that an opportunity existed to advance appropriate PA participation by changing the intensity that people walk for daily transport. The authors did not provide any evidence of reliability for the measures used to examine the PA behaviors of adults with ID.

Temple and Walkley (2003) examined the relationship between proxy generated estimates of PA via diary recordings and accelerometer generated estimates of PA in individuals with ID. Diary recordings were conducted by direct care staff who supervised the participants at home and on outings, and day training staff or work supervisors. The authors found a significant relationship ( $ICC = 0.78$ ) between energy

expenditure measured via the 3-day activity record and the accelerometer. The study also indicated that a majority of the participants' times were spent in sedentary activities. Only 32% of the participants met the Australian National Guidelines minimum requirement of 30 minutes of moderate-intensity PA per day. The authors concluded that regular recording of daily activities by staff working directly with people with ID provides meaningful data because of the relationship with accelerometer output. The authors did not provide any evidence of reliability for the measures used to examine the PA behaviors of adults with ID.

Draheim, Williams, and McCubbin (2003) examined the risk factors of cardiovascular disease between adults with ID who participated in Special Olympics and adults with ID who did not participate in Special Olympics. As part of the study, the researchers used the physical activity questionnaire section of the Third National Health and Nutrition Examination Survey (NHANES) III to assess participants' regular PA habits. Results from this indicated that adults with ID who participated regularly in Special Olympics possessed many lower CVD risk factors when compared to adults with ID who did not participate regularly in Special Olympics. Results also indicated a strong association between self-reported PA with assistance via the NHANES III survey and a decrease in certain cardiovascular disease risk factors. The authors did not provide any evidence of reliability for using self-report with assistance as a measure of PA in adults with ID.

Stanish and Draheim (2005) examined the relationship between walking activity using a pedometer and the physical activity questionnaire section NHANES III survey in adults with MR. The researchers administered the survey through an

interview with the participant and the participant's direct caregiver who assisted with the questions as needed. Pedometer step counts and NHANES III PA survey variables (total number of PA bouts per week, total minutes of PA per week, total number of walking bouts per week, and total minutes of walking per week) were used for analysis. The authors performed a reliability study with a subset of their experimental group and reported reliability coefficients for the four NHANES III PA survey variables mentioned above ( $r = 0.87$ ,  $r = 0.89$ ,  $r = 0.60$ ,  $r = 0.61$ , respectively). The authors found no significant correlations between pedometer step counts and any of the NHANES III PA survey variables. The authors concluded that the two measurements used in the study captured different dimensions of PA. The authors provided no evidence of validity for the use of self-report with assistance as a measure of PA in adults with ID.

### **Issues Concerning the Use of Questionnaires and Secondary Sources**

The use of questionnaires to capture the PA behaviors of adults with ID has been utilized. This information can be used to provide researchers and health organizations with necessary information for a larger representative sample of this population. In many cases, the use of questionnaires developed for the general population is inappropriate for people with ID because of the respondents' inability to comprehend the question and express an answer clearly and because the psychometric properties may not be applicable to this population (Finlay & Lyons, 2001). Finlay and Lyons (2001) also point out that there are a number of difficulties associated with asking questions of people with ID that lead to particular concerns about validity. These difficulties include problems with question content (vocabulary and meaning

should be clear and simple), question phrasing (complex sentence structures), and response format (acquiescence, multiple-choice, open-ended questions).

The validity of conducting the PA questionnaires with the assistance of secondary sources has not been evaluated (Draheim, Williams, & McCubbin, 2002; Temple, Frey, & Stanish, 2006). From the literature reviewed, assistance from secondary sources are typically used to assess PA in this group, but there are some concerns regarding the reliability of this approach because secondary sources may not accurately report primary source behavior (Frey, 2004; Stanish, Temple, & Frey, 2006; Temple, Frey, & Stanish, 2006). This may be true in particular for individuals with ID who live in less controlled settings (i.e. community-based settings). As people with ID are often cared for or supervised by more than one person each day, it is unlikely that a single secondary source would be able to accurately report the PA behavior of a person with ID (Temple, Andersen, & Walkley, 2000). Considering the subjective nature of using questionnaires, issues related to recall and understanding, and questionable reliability of self-report with assistance, additional research is needed to support self-report with assistance from secondary sources as an acceptable method for assessing PA in people with ID (Draheim, Williams, & McCubbin, 2002; Frey, 2004; Stanish, Temple, & Frey, 2006). In studies that have used questionnaires to capture PA participation in adults with ID, an absence of indicators of validity is of concern with most studies that have attempted to measure PA of adults with ID indirectly (Finlay & Lyons, 2001; Temple & Walkley, 2003; Frey, 2004; Stanish, Temple, & Frey, 2006; Temple, Frey, & Stanish, 2006). None of the published studies have provided evidence of validity for using self-report with assistance from

secondary sources to measure physical activity in adults with ID and only one study has provided evidence of reliability for this approach (Stanish & Draheim, 2005).

### **Summary**

There have been few attempts to document PA patterns or to identify factors that influence activity in individuals with ID (Stanish, Temple, & Frey, 2006). More research is needed before researchers and clinicians can draw valid conclusions and make meaningful recommendations pertaining to PA and health promotion among persons with disabilities (Rimmer, Braddock, & Pitetti, 1996). The prevalence of recommended PA and physical inactivity are needed to determine the risk for chronic diseases that may be attributed to inadequate PA in adults with ID (Draheim, Williams, & McCubbin, 2002; Stanish, Temple, & Frey, 2006). Essentially there is an urgent need for an increase in the quality and quantity of research on PA and people with ID (Rimmer, Braddock, & Pitetti, 1996; Stanish, Temple, & Frey, 2006).

Accurate measurement of PA is vital to obtain broad based valid statistics of PA levels among adults with ID and to be able to assess the efficacy and effectiveness of longitudinal interventions (Temple, Frey, & Stanish, 2006). A review of the PA literature on this population has pointed out two major methodological limitations associated with what was measured and how it was measured: accuracy of the measurement instrument and accuracy of the respondents (Temple, Frey, & Stanish, 2006).

It is best to assume that the reliability or validity of a measurement does not generalize to other people unless there is specific evidence that it does (Morrow, 2002). Any decisions made about people based on data that lack validity are at best

questionable and probably in error (Mahar & Rowe, 2002). Researchers should provide comprehensive evidence to support the validity of their measures and the resulting inferences made with their data (Yun & Ulrich, 2002). For individuals with mild ID, many questionnaires developed for the general population may be valid; however this must always be demonstrated rather than assumed (Finlay & Lyons, 2001). Establishing valid and reliable procedures for secondary sources to report on behalf of or in conjunction with adults with ID is a pressing research need (Finlay & Lyons, 2001; Draheim, Williams, & McCubbin, 2002; Frey, 2004; Temple, Frey, & Stanish, 2006). The evidence of validity should be provided by using multiple techniques and evidence to argue the appropriateness of decisions made from data results (Yun & Ulrich, 2002; Temple, Frey, & Stanish, 2006; Warms, 2006).



## APPENDIX B – IRB APPROVAL



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TO: Jeff McCubbin  
 Public Health

IRB #: 3542 – The Validity for Self-Report with Assistance from Proxy to Measure Physical Activity Behavior in Adults with Intellectual Disabilities

Level of Review: Expedited

Expiration Date: 3-17-08

Approved Number of Participants: 65

The referenced project was reviewed under the guidelines of Oregon State University's Institutional Review Board (IRB). The IRB has **approved** the:

( X ) Initial Application                      ( ) Continuing Review                      ( ) Project Revision  
with a (if applicable): ( ) Waiver of documentation of Informed Consent                      ( ) Waiver of Consent

A copy of this information will be provided to the full IRB committee.

- **CONSENT FORM:** All participants must receive the IRB-stamped informed consent document. If the consent is in a format that could not have stamp placement (i.e. web site language, email language, etc), then the language must be **exactly** as the IRB approved it.
- **PROJECT REVISION REQUEST:** Any changes to the approved protocol (e.g. protocol, informed consent form(s), testing instrument(s), research staff, recruitment material, or increase in the number of participants) must be submitted for approval before implementation.
- **ADVERSE EVENTS:** Must be reported within three days of occurrence. This includes any outcome that is not expected, routine and that result in bodily injury and/or psychological, emotional, or physical harm or stress.
- **CONTINUING REVIEW:** A courtesy notice will be sent to remind researchers to complete the continuing review form to renew this project, however – it is the researcher's responsibility to ensure that continuing review occurs prior to the expiration date. Material must be submitted with adequate time for the office to process paperwork. If there is a lapse in approval, suspension of all activity including data analysis, will occur.
- **DEVIATION/EXCEPTIONS:** Any departure from the approved protocol must be reported within 10 business days of occurrence or when discovered.

Forms are available at: <http://oregonstate.edu/research/osprc/rc/humansubjects.htm>.

If you have any questions, please contact the IRB Human Protections Administrator at [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu) or by phone at (541) 737-8008.

*Elisa Espinoza Fallows*

Elisa Espinoza Fallows  
 IRB Human Protections Administrator

Date: 3-18-07

## APPENDIX C – INFORMED CONSENT DOCUMENT



Nutrition and Exercise Sciences  
 Health and Human Sciences, Oregon State University, 101 Milam Hall, Corvallis Oregon 97331  
 T 541-737-2643 | F 541-737-6914 | <http://www.hhs.oregonstate.edu/nes/>

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### INFORMED CONSENT DOCUMENT

Project Title: The Validity for Self-Report with Assistance to Measure Physical Activity Behavior in Adults with Intellectual Disabilities

Principal Investigator: Jeffrey A. McCubbin, Nutrition and Exercise Sciences

Co-Investigators: Marquell Johnson & Joonkoo Yun, Nutrition and Exercise Sciences

We are doing a research study. We are trying to learn more about how well people with intellectual disabilities answer questions about physical activity and how active you are during the week.

This form is about the study, so you can learn about the study and decide if you want to be in the study or not. You can ask any questions. After all of your questions have been answered, you can decide if you want to be in this study or not. Please read carefully.

I understand the following:

1. I am being asked to participate in a study.
2. The researcher wants to find out how well I report my physical activity using a questionnaire with help from my support staff.
3. I can not take part in this study, if I am pregnant.
4. I can not take part in this study, if I am unable to walk.
5. I am being asked to participate for a minimum of 16 days.
6. I can not participate in this study, if I can not get used to wearing activity monitors on my waist.
7. During the study, I will have my weight, height, and waist measurement taken.
8. During the study, I will be asked to respond to questions on my physical activity and dietary intake patterns twice, separated by 1 week.
9. During the study, I will have to wear activity monitors for 7 consecutive days twice.
10. If I am hurt during the study, Oregon State University will not pay for care.
11. My name will not be used in any part of the study.
12. If I complete the study, I will be given a \$20 gift-card to Target.
13. If I stop halfway through the study, I will be given a \$10 gift-card to Target.
14. I want to take part in this study.
15. I can stop taking part in the study at any time. Nothing will happen to me if I do stop.

Oregon State University • IRB Study #:3542 Approval Date: 3/18/07 Expiration Date: 3/17/08

You do not have to be in this study. It is up to you. If you say okay now, but you want to stop later, that's okay too. All you have to do is tell us.

If you have any questions about this research project, please contact: Marquell Johnson at (541) 737-3402, e-mail: [johnmarq@onid.orst.edu](mailto:johnmarq@onid.orst.edu).

You may also contact Jeff McCubbin at (541) 737-5921, e-mail: [jeff.mccubbin@oregonstate.edu](mailto:jeff.mccubbin@oregonstate.edu), or Joonkoo Yun at (541) 737-8584, e-mail: [jk.yun@oregonstate.edu](mailto:jk.yun@oregonstate.edu).

If you have questions about your rights as a participant, please contact the Oregon State University Institutional Review Board (IRB) Human Protections Administrator, at (541) 737-4933 or by email at [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu)

If you want to be in this study, please sign your name.

I, \_\_\_\_\_, want to be in this research study.  
(Print your name here)

\_\_\_\_\_  
(Sign your name here)

\_\_\_\_\_  
(Date)

## APPENDIX D – INSTRUMENTS

Does the participant have Down syndrome? \_\_\_\_\_ Yes \_\_\_\_\_ No

### Modified NHANES III Physical Activity Survey

The Physical Activity (PA) Survey should be given as an interview to the person with ID and a care provider who is familiar with the person's regular routine when possible. A consensus of the person's and the care provider's opinion should be obtained and the most accurate information should be recorded. The PA Survey focuses on the physical activities of the month prior to the assessment only.

1. In the <u>past month</u> , how often did you walk a mile or more at a time without stopping?	_____ (number) times per } _____ day _____ week _____ month	On average, how many minutes do you walk? _____
1a. In the <u>past month</u> , how often did you do other walking?	_____ (number) times per } _____ day _____ week _____ month	On average, how many minutes do you walk? _____
<i>The next questions are about your leisure time physical activity during the past month. We are interested in the following exercises, sports, or physically active hobbies that you might have done.</i> In the <u>past month</u> did you...	In the <u>past month</u> how often did you...	
2. Jog or run? <input type="checkbox"/> YES <input type="checkbox"/> NO	_____ (number) times per } _____ day _____ week _____ month	On average, how many minutes do you jog or run? _____
3. Ride a bicycle or an exercise bicycle? <input type="checkbox"/> YES <input type="checkbox"/> NO	_____ (number) times per } _____ day _____ week _____ month	On average, how many minutes do you bike? _____
4. Swim? <input type="checkbox"/> YES <input type="checkbox"/> NO	_____ (number) times per } _____ day _____ week _____ month	On average, how many minutes do you swim? _____
5. Do aerobics or aerobic dancing? <input type="checkbox"/> YES <input type="checkbox"/> NO	_____ (number) times per } _____ day _____ week _____ month	On average, how many minutes do you do aerobics? _____
6. Do other dancing? <input type="checkbox"/> YES <input type="checkbox"/> NO	_____ (number) times per } _____ day _____ week _____ month	On average, how many minutes do you dance? _____
7. Do calisthenics or exercises? <input type="checkbox"/> YES <input type="checkbox"/> NO	_____ (number) times per } _____ day _____ week _____ month	On average, how many minutes do you dance? _____
8. Garden or do yard work? <input type="checkbox"/> YES	_____ (number) times per } _____ day _____ week	On average, how many minutes do you



<input type="checkbox"/> NO	__ month	garden or do housework? ____
9. Lift weights? <input type="checkbox"/> YES <input type="checkbox"/> NO	____ (number) times per } __ day __ week __ month	On average, how many minutes do you lift weights? ____

Please ask the person and the care provider the following questions. Probe to see if the athlete has participated in any other physical activities in the last month.

10. In the <u>past month</u> , have you done any other exercises, sports, or physically active hobbies not mentioned? <input type="checkbox"/> YES <input type="checkbox"/> NO	In the <u>past month</u> how often did you...?	
11. PROBE: What? <input type="checkbox"/> YES <input type="checkbox"/> NO	____ (number) times per } __ day __ week __ month	On average, how many minutes do you (activity)? ____
12. PROBE: Any others? <input type="checkbox"/> YES <input type="checkbox"/> NO	____ (number) times per } __ day __ week __ month	On average, how many minutes do you (activity)? ____
13. PROBE: Any others? <input type="checkbox"/> YES <input type="checkbox"/> NO	____ (number) times per } __ day __ week __ month	On average, how many minutes do you (activity)? ____
14. PROBE: Any others? <input type="checkbox"/> YES <input type="checkbox"/> NO	____ (number) times per } __ day __ week __ month	On average, how many minutes do you (activity)? ____

## Fat Screener - Berkeley Nutrition Services

ID # \_\_\_\_\_ Date \_\_\_\_\_  
Gender \_\_\_\_\_ Male \_\_\_\_\_  
\_\_\_\_\_ Female \_\_\_\_\_ Age \_\_\_\_\_

Think about your eating habits over the past year or so. About how often do you eat each of the following foods? Remember breakfast, lunch, dinner, snacks and eating out. Check one radio button for each food.

<b>Meats and Snacks</b>	<b>1/MONTH or less</b>	<b>2-3 times a MONTH</b>	<b>1-2 times a WEEK</b>	<b>3-4 times a WEEK</b>	<b>5+ times a WEEK</b>
Hamburgers, ground beef, meat burritos, tacos	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Beef or pork, such as steaks, roasts, ribs, or in sandwiches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fried chicken	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hot dogs, or Polish or Italian sausage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cold cuts, lunch meats, ham (not low-fat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bacon or breakfast sausage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Salad dressings (not low-fat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Margarine, butter or mayo on bread or potatoes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Margarine, butter or oil in cooking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<b>1/MONTH or less</b>	<b>2-3 times a MONTH</b>	<b>1-2 times a WEEK</b>	<b>3-4 times a WEEK</b>	<b>5+ times a WEEK</b>
Eggs (not Egg Beaters or just egg whites)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pizza	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cheese, cheese spread (not low-fat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whole milk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French fries, fried potatoes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Corn chips, potato chips, popcorn, crackers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doughnuts, pastries, cake, cookies (not low-fat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ice cream (not sherbet or non-fat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX E – INFORMATION FOR PARENTS/LEGAL GUARDIANS/CARE  
PROVIDERS



Nutrition and Exercise Sciences  
 Health and Human Sciences, Oregon State University, 101 Milam Hall, Corvallis Oregon 97331  
 T 541-737-2643 | F 541-737-6914 | <http://www.hhs.oregonstate.edu/nes/>

## **INFORMATION FOR PARENTS / LEGAL GUARDIANS/CARE PROVIDER**

Project Title: The Use of Physical Activity Questionnaires with Proxy to Measure Physical

Activity Behavior in Adults with Intellectual Disabilities

Principal Investigator: Jeffrey A. McCubbin, Nutrition and Exercise Sciences

Co-Investigators: Marquell Johnson & Joonkoo Yun, Nutrition and Exercise Sciences

### **WHAT IS THE PURPOSE OF THIS STUDY?**

The research study will examine how accurate adults with intellectual disabilities self-report their physical activity behaviors on questionnaires with the assistance of a proxy (i.e. care provider/parent). It is thought that adults with intellectual disabilities inaccurately self-report their physical activity behavior on questionnaire even with the assistance of a proxy. Further research is needed in this area to support self-report with the assistance of proxy as an acceptable method for assessing physical activity in people with intellectual disabilities.

This is a student dissertation. The results may be presented at a conference and published in a professional journal.

### **WHAT IS THE PURPOSE OF THIS FORM?**

This consent form gives you the information you will need to decide, together with your dependent, whether or not he/she will be in the study. Please read the form carefully. You may ask any questions about the research, the possible risks and benefits, the rights of your dependent as a volunteer, and anything else about the research or this form that is not clear. When all of your questions have been answered, you can decide, together with your dependent, whether or not he/she will participate in the study.

### **WHY IS MY DEPENDENT BEING INVITED TO TAKE PART IN THIS STUDY?**

We are inviting your dependent to participate in this study because she/he is a healthy adult age 18+ years and older who has mild-to-moderate intellectual disability. She/he can not participate in the study if she/he has bone disease/joint pain, or leg injuries that prevent them from walking. She/he can not participate in this study if she/he is not ambulatory. Moreover, she can not participate in the study if she is pregnant.

### **WHAT WILL HAPPEN DURING THIS STUDY AND HOW LONG WILL IT TAKE?**

All assessment and study procedures will be completed at the dependents' residences. The researcher will meet with parents/legal guardians/ or direct care provider and the dependent. Demographic information will be collected on the dependents, such as, age, gender, intellectual condition (Down syndrome and non-Down syndrome), etc. Demographic information will also be collected on the parents/legal guardians, such as, relationship to the dependent with intellectual disabilities, gender, age, average daily time spent with the dependent.

After collecting the demographic information from the dependent and the parent/legal guardian or direct care provider, height and weight will be measured with the dependent dressed in lightweight clothing. Waist circumference will be measured also. These measures should take about 15 minutes.

Following the measuring of height, weight, and waist circumference two questionnaires will be used to find out physical activity and dietary intake patterns. The questionnaires will be administered through an interview with the dependent and the parent/legal guardian to with questions. The questionnaires will take approximately 20-30 minutes. The two questionnaires will be administered to the dependent and the parent/legal guardian twice, separated by approximately 1-week.

Finally, accelerometers (movement counter) and pedometer (step counter) will be shown and demonstrated to the dependent and the parent/legal guardian. The accelerometer and pedometer will be placed in a pouch and attached to an elastic belt positioned over the right hip. The accelerometer will be worn for 7 consecutive days, twice, separated by approximately 1 week. Dependents' will have to wear the accelerometers during waking hours, except when bathing or participating in water activities, throughout the 7-day assessment period. Overall the research study will require 16 days of participation.

### **WHAT ARE THE RISKS OF THIS STUDY?**

The risk associated with physical activity in apparently healthy individuals is very low. All other measurement tools used in this study have minimal or no risk involved (i.e. accelerometers, pedometers, and questionnaires). In the event of research related injury, compensation and medical treatment is not provided by Oregon State University or the researchers of this study.

### **WHAT ARE THE BENEFITS OF THIS STUDY?**

The products of this study will provide participants a summary of their physical activity and dietary intakes. The results are important for researchers who study

physical activity behavior of adults with ID and for those who develop physical activity interventions for this population. At the end of the study, the researchers will discuss with participants the positive health benefits of being physically active and offer suggestions for exercise training.

### **WILL I OR THE PARTICIPANT BE PAID FOR PARTICIPATING?**

Participation in this study is voluntary. In addition, your dependent will receive a \$20 gift-card to Target, if she/he completes the study. She/he will receive a \$10 gift card to Target if she/he decides to withdraw part way through a session. You will be paid (\$10 gift card to Target) if you are the one to assist your dependent in answering the questionnaires.

### **WHO WILL SEE THE INFORMATION I AND THE PARTICIPANT GIVE?**

The information you and the participant provide during this research study will be kept confidential to the extent permitted by law. To help protect your dependent's confidentiality, we will identify her/him on our computers with a code number. Her/his name is to remain confidential in the analysis of any information regarding this study. All information, including questionnaires, informed consent documents, and study results will be securely stored and accessible only to the primary investigator and researchers named in this study. At your request, a copy of your dependent's results will be given to you. If the results of this research are published your and the participant's identities will not be made public.

### **DO WE HAVE A CHOICE TO BE IN THE STUDY?**

If you and your dependent decide that she/he may take part in the study, it should be because she/he really wants to volunteer. You may choose to not allow her/him to take part at all. If you decide that she/he should not volunteer, the participant will not lose any benefits or rights she/he would normally have. If both of you agree that she/he may participate in this study, she/he may stop participating at any time. If you decide that the dependent withdraw from this project before it ends, the researchers may keep information collected about her/him and this information may be included in study reports. If you decide not to take part in this study, your decision will have no effect on the quality of care, services, etc., you receive.

### **WHAT IF I HAVE QUESTIONS?**

If you have any questions about this research project, please contact: Marquell Johnson at (541) 737-3402, e-mail: [johnmarq@onid.orst.edu](mailto:johnmarq@onid.orst.edu).

You may also contact Jeff McCubbin at (541) 737-5921, e-mail: [jeff.mccubbin@oregonstate.edu](mailto:jeff.mccubbin@oregonstate.edu), or Joonkoo Yun at (541) 737-8584, e-mail: [jk.yun@oregonstate.edu](mailto:jk.yun@oregonstate.edu).

If you have questions about your dependent's rights as a participant, please contact the Oregon State University Institutional Review Board (IRB) Human Protections Administrator, at (541) 737-4933 or by email at [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu).

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Your signature indicates that this research study has been explained to you, that your questions have been answered. It also indicates that you agree to allow your dependent to take part in this study. You will receive a copy of this form.

Name of Participant (printed):

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(Name of Parent/Guardian or Legally  
Authorized Representative – printed)

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(Relationship to Participant - printed)

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(Signature of Parent/Guardian or  
Legally Authorized Representative)

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(Date)

## APPENDIX F – LETTER OF INVITATION TO SERVICE PROVIDERS





Nutrition and Exercise Sciences  
Health and Human Sciences, Oregon State University, 101 Milam Hall, Corvallis Oregon 97331  
T 541-737-2643 | F 541-737-6914 | <http://www.hhs.oregonstate.edu/nes/>

Dear Sir or Madam,

We would like to take this opportunity to invite your clients who have Intellectual Disabilities to participate in a research study conducted by Oregon State University. The study will examine whether persons with intellectual disabilities with the assistance of a secondary source (i.e. care provider, group home staff, and/or legal guardian) can self-report their physical activity behaviors on a questionnaire.

Physical activity is defined as any bodily movement that requires energy. It can include exercise, sports participation, house and gardening work, walking, etc. Questionnaires with the assistance of a secondary source have been used to examine the physical activity behavior of adults with intellectual disabilities. However, there is limited evidence to support that the information from the use of questionnaires accurately represents physical activity behavior. A better understanding of how well questionnaires with the assistance of a proxy provide accurate information of physical activity behavior may increase the ability of researchers to identify physical activity interventions that are most suitable for adults with intellectual disabilities.

We will be measuring physical activity behavior and dietary intake in adults with intellectual disabilities. A minimum of 16 days is required. Adults with intellectual disabilities will be asked to wear an accelerometer for a week, and then will be interviewed with their secondary source for 45 minutes to answer questions on a physical activity and diet questionnaire. These procedures will be repeated for the following week. Individuals with intellectual disabilities who complete all study requirements and return activity monitors will receive a \$20 gift-card to Target for their participation and they will be advised on healthy exercise habits.

Male and female adults aged 18 and older who have mild-to-moderate forms of intellectual disability may participate in the study.

If you know of individuals in your program that would be interested in our study or if you have additional questions, please call:

Marquell Johnson at (541) 737-3402, e-mail: [johnmarq@onid.orst.edu](mailto:johnmarq@onid.orst.edu), or

Jeff McCubbin at (541) 737-5921, e-mail: [jeff.mccubbin@oregonstate.edu](mailto:jeff.mccubbin@oregonstate.edu).  
Thank you for your time in assisting this research project.

Sincerely,

Jeff McCubbin, Ph.D.  
Associate Dean and Professor  
College of Health and Human Sciences

Marquell Johnson, M.S., C.S.C.S.  
Doctoral Candidate  
Nutrition and Exercise Sciences

## APPENDIX G – ADVERTISING FOR RECRUITMENT



Nutrition and Exercise Sciences  
 Health and Human Sciences, Oregon State University, 101 Milam Hall, Corvallis Oregon 97331  
 T 541-737-2643 | F 541-737-6914 | <http://www.hhs.oregonstate.edu/nhs/>

## Research Participants Wanted

### Who is eligible?

Adults with Intellectual Disabilities:

- Aged 18 and older
- Who reside in community settings (Group homes, with family, independently, etc)
- With mild-moderate intellectual disabilities

### What is involved for participants?

The study involves us coming to the participant's home for a series of assessments, including **activity monitoring, body measurements, dietary questions, and physical activity questions**. Study procedures require a minimum of 16 days of participation. Participants will also be compensated for their time and efforts (**\$20 gift card**). Care providers will also be compensated for their time.

To obtain these assessments, each participant will have:

- **Wear an accelerometer and pedometer for 7 consecutive days twice**
- **Two questionnaires on diet and physical activity given twice**
- **Body measurements including height, weight, and around the hips to measure body fat**

All Participants will get feedback on their results!!

If you have any concerns or questions feel free to contact us at any time. We can be reached by phone at 541-737-3402 or by e-mail at [johnmarq@onid.orst.edu](mailto:johnmarq@onid.orst.edu).

Marquell Johnson, M.S., C.S.C.S  
 Student Researcher

Jeff McCubbin, Ph.D.  
 Researcher

**We are willing to come to your facility to talk with potentially interested participants about our project.**

If you have questions about the participant's rights, please contact the Oregon State University Institutional Review Board (IRB) Human Protections Administrator, at (541) 737-4933 or by email at [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu).

APPENDIX H – STUDY ANNOUNCEMENT FOR ARC OF BENTON COUNTY  
NEWSLETTER

Do You Remember the Physical Activities that You Do Each Week? If So, You  
Can Receive a Gift Card

Researchers at Oregon State University are trying to learn more about how well people with intellectual disabilities answer questions about physical activity and how active they are during the week. The study involves us coming to the participant's home to get answers to questions about **diet and physical activity, to take height, weight, and waist measurements, and to monitor activity level**. The study requires a minimum of 16 days of participation. Participants who complete the study will be compensated for their time and efforts (**\$20 gift card**). Care providers will also be compensated for their time if they assist with questions (**\$10 gift card**). If you are interested in participating, please contact: Marquell Johnson at (541) 737-3402, email: [johnmarq@onid.orst.edu](mailto:johnmarq@onid.orst.edu)

APPENDIX I – SCRIPT FOR INITIAL CONTACT WITH POTENTIAL  
PARTICIPANTS

### **Script for Initial Contact with Potential Participants**

Potential Participant (PP): Hello, I'm interested in your study. Please tell me what it is about?

Researcher (R): This study is about how well you are able answer questions about your physical activity, like walking, running, dancing, and swimming. You will be allowed to have help from your group home staff (parent, case manager), with these questions. First we would meet so you could meet me, answer the physical activity questions and I would measure you for your height and weight. I would also take a measurement around your waist.

We would meet in a place that is most comfortable for you and all the information that you share with me will be kept secret. Also during this meeting I would show you the next part of the study which is wearing activity monitors for 2 weeks. I will show you the activity monitors so you know how to use them and how to wear them.

PP: Why do I have to wear these things around my waist?

R: The part of the study will show me how much you are active for two week. If you agree to help me and participate in this study, you will be given a \$20 gift card to Target after you have completed the 2 weeks and have returned the activity monitors. Does this sound like something you would like to do?

PP: Yes or No, if yes will set up a time to meet.

## APPENDIX J – PARTICIPANT’S RAW DATA



ID Number	PA Bouts	1 PA Bouts	2 PA Avg	AC Week 1	AC Week 2	AC Avg	AC Avg/7	SC Week 1	SC Week 2	SC Avg	SC Avg/7	FI 1	FI 2	F Avg
000	15	17	16	721914	522408	622161	88880.14	21086	15995	18540.5	2648.64	3	3	3
001	11	15	13	670315	503599	586957	83851.00	34721	19647	27184	3883.43	3	3	3
002	6	7	6.5	2223415	1450095	1836755	262393.57	66202	44291	55246.5	7892.36	3	3	3
003	12	12	12	507214	607311	557262.5	79608.93	27999	20785	24392	3484.57	3	2	2.5
004	6	23	14.5	884213	885596	884904.5	126414.93	38830	40140	39485	5640.71	3	2	2.5
005	8	11	9.5	1554569	1272103	1413336	201905.14	53852	45826	49839	7119.86	3	3	3
006	18	16	17	1000659	916452	958555.5	136936.50	53250	51021	52135.5	7447.93	1	2	1.5
007	6	8	7	747606	956047	851826.5	121689.50	38744	33907	36325.5	5189.36	3	3	3
008	19	11	15	1391665	1392895	1392280	198897.14	76904	78502	77703	11100.43	3	3	3
009	26	22	24	1600708	1299685	1450197	207170.93	67055	74972	71013.5	10144.79	1	1	1
010	13	9	11	693857	851610	772733.5	110390.50	42657	49580	46118.5	6588.36	2	2	2
011	19	24	21.5	1732257	1549187	1640722	234388.86	81578	79248	80413	11487.57	3	2	2.5
012	23	13	18	968025	724537	846281	120897.29	72311	68113	70212	10030.29	1	1	1
013	11	10	10.5	646038	657953	651995.5	93142.21	27751	28457	28104	4014.86	3	3	3
014	18	10	14	1015691	797443	906567	129509.57	59619	56418	58018.5	8288.36	2	1	1.5
015	8	6	7	503573	430788	467180.5	66740.07	19177	17750	18463.5	2637.64	3	3	3
016	9	10	9.5	902223	905832	904027.5	129146.79	52283	44462	48372.5	6910.36	2	2	2
017	9	9	9	550122	446181	498151.5	71164.50	28742	26407	27574.5	3939.21	2	3	2.5
018	5	11	8	2089060	1136776	1612918	230416.86	83996	78996	81496	11642.29	3	3	3
019	11	16	13.5	1503385	1569391	1536388	219484.00	91833	108015	99924	14274.86	3	3	3
020	7	6	6.5	1070489	1089300	1079895	154270.64	53128	51741	52434.5	7490.64	2	1	1.5
021	12	14	13	562192	531739	546965.5	78137.93	39741	35238	37489.5	5355.64	2	2	2
022	12	9	10.5	436301	414439	425370	60767.14	11220	16369	13794.5	1970.64	2	2	2
023	25	17	21	1041406	827908	934657	133522.43	75783	50295	63039	9005.57	1	2	1.5
024	11	13	12	527470	915382	721426	103060.86	20406	27398	23902	3414.57	3	3	3
025	2	6	4	547069	477028	512048.5	73149.79	23154	30744	26949	3849.86	3	3	3
026	4	5	4.5	1105547	944487	1025017	146431.00	55552	42240	48896	6985.14	2	2	2
027	18	22	20	1293377	1204810	1249094	178441.93	76931	67579	72255	10322.14	2	2	2
028	22	22	22	1569266	1130248	1349757	192822.43	95856	83872	89864	12837.71	2	3	2.5
029	11	4	7.5	402913	430184	416548.5	59506.93	19946	24978	22462	3208.86	3	3	3
030	9	7	8	418538	368262	393400	56200.00	16637	12560	14598.5	2085.50	2	3	2.5
031	4	9	6.5	918615	999176	958895.5	136985.07	33511	46273	39892	5698.86	2	2	2
032	22	24	23	1160878	1167190	1164034	166290.57	51394	50562	50978	7282.57	2	3	2.5
033	7	7	7	419472	340044	379758	54251.14	17378	20910	19144	2734.86	2	2	2
034	21	26	23.5	918438	1019088	968763	138394.71	57019	68549	62784	8969.14	2	2	2
035	15	11	13	901126	715696	808411	115487.29	46529	54701	50615	7230.71	2	2	2
036	10	15	12.5	422960	331985	377472.5	53924.64	18168	19652	18910	2701.43	2	3	2.5