

Health and Health Promotion Research Projects

Exercise Adherence among Adults with Down Syndrome

TAMAR HELLER, JAMES RIMMER, KELLY HSIEH, AND BETH MARKS

Adults with Down syndrome (DS) have low fitness levels (Fernhall & Pitetti, 2001; Fernhall, Tymeson, Millar, & Burkett, 1989; Fernhall et al., 1996; Graham & Reid, 2000; Pitetti, Climstein, Campbell, Barrett, & Jackson, 1992), a high incidence of obesity (Rimmer, 2000; Rimmer, Braddock, & Marks, 1995; Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998), and tend to lead sedentary lives (Hoge & Dattilo, 1995). They are also at a higher risk than the general population of developing secondary conditions and age-related declines at an earlier age than the general population (Chicoine, Rubin, & McGuire, 1997; Janicki, Heller, Seltzer, & Hogg, 1996; Pitetti & Campbell, 1991). Despite the well-documented evidence of the health and psychosocial benefits of participating in regular moderate to vigorous physical activity for people without disabilities (Pate et al., 1995; U.S. Department of Health, 1996), little research has been conducted on interventions to promote increased physical activity of persons with DS and other intellectual disabilities (ID). Recently, a report from the Office of the Surgeon General called attention to the poor health status of persons with intellectual disability and the need for health promotion programs that will increase physical activity and reduce obesity in this population (U.S. Department of Health, 2002).

Although several researchers have focused on the impact of exercise training on fitness measures (Millar, Fernhall, & Burkett, 1993; Rimmer, Heller, Wang, & Valerio, 2004; Varela, Sardinha, & Pitetti, 2001), few empirical studies have focused on the impact of a physical activity and health education program on the

physiological and psychosocial well-being of adults with ID (Bluechardt & Shepard, 1995; Schurrer, Weltman, & Brammell, 1985). Limited research has been done to determine effective ways to encourage exercise adherence in this population. Furthermore, research has not examined the cognitive–emotional factors that can potentially hinder or facilitate exercise adherence. In the present study we examine the impact of an exercise and health education program on the physiological, metabolic, exercise attitudes, and psychosocial outcomes of middle-age and older adults with Down syndrome.

Conceptual/Theoretical Model. Two major perspectives concerning how persons change health practices guided this study: 1) the Transtheoretical Model of Behavior Change (Prochaska et al., 1994; Prochaska & DiClemente, 1992) and Bandura's Social Cognitive Theory of Social Learning Theory (Bandura, 1982; 1986; 1997). The Transtheoretical Model states that persons change their health behaviors by proceeding through a process of stages: *precontemplation* (no thought of changing), *contemplation* (aware of need to change), *preparation* (takes small steps), *action* (modifies behavior), and *behavior maintenance* (incorporates



change into routine). The model allows us to understand when particular shifts in attitudes, intentions, and behaviors occur. According to this model, pre-treatment stages of change are associated with movement to active participation in exercise activities (Marcus, Rakowski, & Rossi, 1992). This model includes the concept of decisional balance, which refers to one's evaluation of the personal gains and losses with changing behavior. Marcus and colleagues found that individuals are more likely to exercise if the perceived gains outweighed the perceived losses. No study to date has examined the applicability of this model to persons with ID.

Bandura's Social Cognitive Theory posits that behavior change is a function of setting goals based on outcome expectations associated with the behavior change, the tasks required to achieve those goals, and self-efficacy expectations for achieving the goals (Bandura, 1982; 1986; 1997). Thus, individuals are more likely to change their exercise behaviors if they believe that: a) their current lifestyles pose threats to personally valued goals; b) exercise behaviors will help reduce the threat (outcome expectations); and c) they are personally capable of adopting the new behaviors (self-efficacy expectations). This theory has been applied widely to the study of health behaviors. Self-efficacy has been shown to be a major predictor of adherence to preventive health programs (O'Leary, 1985), and to exercise involvement (McAuley, Lox, & Duncan, 1993). Bandura also emphasizes the informative and motivational role of reinforcement and observational learning through modeling the behavior of others. Hence, environmental cues, including support from others, play an important role. Berkman (1995) notes that interventions aimed at restructuring naturally

occurring networks will be more effective than those that rely on short-term constructed support groups. A few exploratory studies suggest that social support is essential in promoting positive health behaviors for adults with ID (Fox, et al., 1985; Fujiura et al., 1997). The present study is designed to investigate the applicability of both the transtheoretical model in delineating stages of behavioral change and the social cognitive model in explaining the factors predicting long-term adherence to an exercise program among adults with a lifelong cognitive disability, such as adults with ID.



Study Purpose and Objectives

The overall aims of the project were to 1) test the efficacy of a physical exercise program for adults with ID and 2) test the applicability of the Transtheoretical Model and Social Cognitive Theory for predicting long-term adherence to enhanced levels of physical activity in this population.

The project had the following hypotheses:

1. Participants in both treatment groups will exhibit enhanced physical activity and improved physiological, adaptive functioning, and psychosocial functioning compared to controls immediately after the training.

2. Participants in the group that also received a caregiver education program will exhibit significantly greater levels of physical activity adherence over time in comparison with the other treatment group and with the controls.
3. Persons in the caregiver education group will have significantly enhanced physiological, adaptive functioning, and psychosocial outcomes in comparison with the other treatment group and with the controls.
4. Decisional balance (of pros versus cons of exercising) and perceived exercise self-efficacy will predict long-term exercise adherence.

Sample Population and Methodology

A total of 89 adults with Down syndrome ages 30 years and older with mild to moderate intellectual disabilities were recruited to participate in the health promotion study. The criterion of age 30 years and above was chosen because many adults with ID (e.g., those with DS) experience age-related declines earlier than the general population (Heller, 1997). Individuals with more severe ID were excluded since they were not likely to develop an adequate understanding of the importance of exercise and because reliability of measures would not be adequate for this research study. The sample included adults living in and out of the family home.

Fifty-three participants completed pre- and post-assessments. The intervention group contained 32 participants who completed a 12-week exercise and health education program. Twenty-one participants in the control group received no training. Participants' mean age was 39.72 years (range = 30 to 54). Fifty-five percent were female, 60% were Caucasian, 32%, African American, and 8%, Hispanic. Over half of the participants (57%) lived with a family member, 11% lived on their own, and the remainder (32%) lived in small or large supervised residences. From informant reports, the most common medical conditions were speech disability (64%), vision impairment (28%), thyroid/other glandular disorder (26%), hearing impairment (15%), and heart condition (13%). Sixty-

seven percent of carer informant surveys were filled out by staff members and the remainder, by family members.

Pre-screening evaluation protocol. Before any participant began the exercise training, they completed a medical history questionnaire and a Clearance Form, developed by the American College of Sports Medicine. Participants who received clearance from the project medical director following the graded exercise test were eligible for the study. The evaluation included baseline measurements of cardiopulmonary fitness, muscular strength and endurance, flexibility, body composition, blood pressure, blood lipids, and blood glucose.

Center-based fitness intervention. After baseline assessments, participants were randomly assigned to an intervention or control group. The intervention included a 12-week, 3 days per week program lasting 3 hours a day. Each day participants had three 1-hour classes, including exercise, health education, and nutrition. The center based fitness intervention program was conducted at the DHD Center on Health Promotion for Persons with Disabilities.

The exercise intensity level was geared to the participant's initial fitness level. Every attempt was made to adhere to the guidelines established by the American College of Sports Medicine and the Surgeon General's Report on Physical Activity and Health, which states that a moderate level of activity is needed to achieve health benefits. The goal was to expend a minimum of 150 kilocalories per exercise session. Muscular strength and endurance activities were performed at 60 to 75% of 1-RM (1 Repetition Maximum).

The exercise modalities varied according to the preferences of the participant. Cardiorespiratory fitness activities included walking, stationary cycling, Nu-step recumbent stepping, arm ergometry, and low impact aerobics. For muscle strength and endurance, subjects performed calisthenics and used small equipment such as hand weights and elastic tubing.

Participants did 30 to 40 minutes per session the first two weeks and began the one-hour sessions at the

beginning of the third week. The first two weeks were also used to familiarize participants with the equipment and to determine the type of exercises they wanted to do. The exercise intervention consisted of aerobic activity, muscle strength and endurance, and flexibility.

Four 12-week exercise sessions were conducted with 7 to 8 participants in each iteration. The exercise classes were supervised by a full-time registered clinical exercise physiologist and two assistants. The exercise classes consisted of 30 to 45 minutes of cardiovascular exercise and 15 to 20 minutes of muscular strength and endurance. The first few minutes (3 to 5) of cardiovascular exercise was used as a light warm-up and the last (3 to 5) were used as a cool down. During the first 2 weeks of the program, participants were taught how to use the equipment safely (i.e., getting on and off the machine) and were instructed on how to let the staff know when they were experiencing any unusual symptoms (i.e., chest hurts, dizziness). Participants exercised for 15 to 20 minutes in their prescribed target heart rate zone. During Weeks 3 and 4, emphasis was placed on reaching and maintaining their prescribed training levels for 20 to 30 minutes on one or more of the following machines: recumbent stepper, stationary cycle (recumbent and upright), treadmill, and elliptical cross-trainer. Participants selected their own equipment. By Week 5, all participants were exercising for 30 minutes in their designated training zone (50% to 70% peak VO₂). Polar Vantage XL heart watch monitors (Port Washington, NY) were programmed for each participant (upper and lower training heart rate) to assure that they were exercising in the appropriate target heart rate zone. Each project staff member was responsible for one to three participants to assure that they maintained their heart rate in the appropriate training zone. Strength training was initiated at 70% of the participants' 1-RM for one set of 10 to 20



repetitions. When participants were able to complete 20 repetitions for two consecutive sessions with proper lifting technique, the weight was increased by 10% of their 1-RM.

Free transportation to the center was provided to participants. Encouraging phone calls were used to keep the participants interested in the program. Finally, certificates and awards were presented to participants once they completed the program.

Health education component for adult with ID. The RRTC's later life planning peer training program for older adults with ID (Heller et al., 1996), which includes 4 two-hour sessions on developing personal goals in the areas of health and wellness and leisure and recreation, was used to develop the *Exercise and Nutrition Health*

Education Curriculum for Adults with Developmental Disabilities (Heller, Marks, & Ailey, 2001a). The curriculum was a 12-week interactive program that included groups of 6 to 10 participants at a time. Each week, participants had three 1-hour sessions, where they were encouraged to understand their attitudes toward health, food and exercise; gain skills and knowledge about healthy eating and exercising; identify food and exercise preferences; participate in food preparation and exercise activities; and, locate places in their community where they could exercise regularly. Strategies woven throughout this curriculum included making choices, self-determination, self-efficacy, self-advocacy, rights and responsibility, problem-solving techniques, and conflict resolution.

The *Exercise and Nutrition Health Education Curriculum for Adults With Developmental Disabilities* (Heller, Marks, & Ailey, 2001), which is based on two theoretical frameworks, including Bandura's (1982; 1986; 1997) Social Cognitive Theory of Social Learning and the Transtheoretical Model of Behavior Change (Prochaska, DiClemente, & Norcross, 1992). This curriculum was designed to

help participants with developmental disabilities a) understand the benefits of health promoting behaviors specific to their lifestyle (outcome expectations), b) increase their self-efficacy in performing exercise, and c) develop health promotion goals and action plans that derive from their personal preferences. To increase their perceptions that they can exercise effectively, participants exercised in a group setting, received reinforcement for their participation, as well as a videotape of themselves exercising to take home after the training. To facilitate observational learning, a peer trainer who had a developmental disability co-facilitated some of the classes, along with the research staff members (nurses and graduate students in nursing, public health, and occupational therapy).

The 36 modules of the curriculum are divided into five sections comprising the phases outlined in the transtheoretical model: Precontemplation, Contemplation, Preparation, Action, and Maintenance. Topics covered were a) understanding attitudes towards health, food, and exercise; b) gaining skills and knowledge about exercising and healthy eating; and c) identifying barriers and supports for exercising and healthy eating. Participants received their own personalized workbook to take home during and after the training. These easy-to-read workbooks included graphic and pictorial representations, such as photos of each participant exercising, newsletters covering the lessons learned each week, and the written goals and the plan that participants developed to achieve these goals.

Education component for caregivers. The caregiver education program was provided to the primary support person of the adult with ID (family member or residential provider). The aim of this curriculum was to motivate support persons to help and support the adult with ID to set health promotion goals, develop action plans, and to attain these goals. The education program was held for two hours every other week (6 sessions) during the same time that the



individuals with ID were receiving their education and exercise intervention. Three of the education sessions were held jointly with the individual with ID.

Data Collection and Measures

Recruitment. Participants were identified and recruited through key personnel at day programs and residential agencies in the Chicago area. Agency staff made the initial contact with participants. The primary carer (staff or family member) filled out a survey on demographics, health status, exercise participation, and adaptive behavior information. Interviews were conducted both at the day or residential programs and on-site at a university-based health promotion center. Transportation was provided to participants.

Demographics and health. Demographic information was collected on each participant, along with information about health conditions, self-rated health status, exercise status, and adaptive behavior.

Cognitive-emotional barriers to exercise. The *Cognitive-Emotional Barriers to Exercise Scale* (Heller, Hsieh, & Rimmer, 2002; Heller, Rimmer, & Rubin, 2001) includes 9 items about barriers towards exercise participation. The barriers include lack of time, lack of interest, lack of energy, perception that exercise is boring, will not improve condition, will make condition worse, is too difficult, has health concerns, and are too lazy. It is rated on a 3-point Likert scale from 1 (*not a barrier*) to 3 (*yes, a barrier*) for the person with Down syndrome. The Cronbach's alpha reliabilities were .78 and .67 for baseline and posttest, respectively. The test-retest correlation was .47.

Outcome expectations. Perceived expected outcomes were measured using the *Exercise Perceptions Scale* (Heller & Prohaska, 2001). The instrument includes 9 items (control weight, feel less tired, make body feel good, feel happier, hurt less, meet new people, get in shape, look better, and improve health) assessing the perceived benefits of exercise for oneself (self-rating). This instrument is

measured on a 3-point Likert scale. Cronbach's alpha reliabilities were .81 and .76 for baseline and posttest, respectively. The test-retest correlation was .72.

Performance self-efficacy. The *Self-Efficacy Scale* (Heller, 2001b) contains 5 items pertaining to the confidence that one has in performing exercise, including being able to use various kinds of exercise equipment and feeling comfortable performing strength and cardiovascular exercises. Confidence is rated on a continuum from 1 (*not at all sure*) to 3 (*totally sure*). This scale was adapted from the *Self-Efficacy to Exercise Regularly Scale* of the *Lorig Self-Efficacy to Perform Self-Management Behaviors* instrument (Lorig, Chastain, Ung, Shoor, & Holman, 1989). The alpha reliabilities were .83 and .78 for baseline and posttest, respectively. The test-retest correlation was .52.

Community integration. We assessed involvement in social and community activities with the *Community Integration Scale* (Heller & Factor, 1991). We asked participants whether they took part in nine activities, including talking with family/friend on the phone, visiting friends outside of the residence, and going to movies, shops, restaurants, and church in the last month. The scale is rated 1 (yes) or 0 (no) on each activity. Test-retest reliability was .63.

Depression scale. Depression was assessed with the *Children's Depression Inventory* (Kovacs, 1992), which has been adapted for adults with intellectual disabilities. This scale contains 10 items, each of which has three statements (i.e., I am sad once in a while, I am sad many times, I am sad all the time). The range of possible scores is 0 to 20. The cutoff score for reported depression is 6 or above. Cronbach's alpha was .73 at baseline and .65 at posttest. Test-retest reliability was .58.

Life satisfaction. Life satisfaction was assessed using the *Life Satisfaction Scale* (Heller, Sterns, Sutton, & Factor, 1996), which was developed specifically for adults with intellectual disabilities.



Domains are Satisfaction with Health, Leisure/Recreation, Work, Residence, and Social Support; 19 items are included, which are measured on a 3-point Likert scale from 1 (*not happy*) to 3 (*very happy*). Cronbach's alpha reliabilities for baseline and

posttest were .89 and .81, respectively. Test-retest reliability was .60.

Peak oxygen uptake (cardiovascular fitness). Peak VO₂ was assessed with a SensorMedics 2900 Metabolic Cart (Yorba Linda, CA) under the supervision of a physician and exercise physiologist.

Strength. We assessed strength using the LifeFitness (Franklin Park, IL) bench press and seated leg press machines. The participants performed a 1-RM on each machine using the procedures outlined by the American College of Sports Medicine (2000, pp. 81–82). Handgrip strength was measured with a Grip-A handgrip dynamometer.

Body composition. Height, weight, and skinfold measures were recorded by a trained tester using the procedures of Lohman, Roche, and Martorell (1991). Skinfold measurements were taken with a Harpenden skinfold caliper (West Sussex, England) at the chest, abdomen, and thigh locations for men and triceps, suprailiac, and thigh locations for women. Overweight and obesity was determined from the Body Mass Index (BMI), the criteria established by the Expert Panel on the Identification, Evaluation, and Treatment of Overweight in Adults (1998).

Data Analysis

We used *t* tests to examine whether there were group differences among the continuous demographic variables (age, level of adaptive function, self/informant-rated health status, number of medical

conditions) at baseline. For the categorical demographic variables (gender, race, level of intellectual disability, residential status, informant relationship, and exercise participation), chi-square tests were employed to detect group differences. We employed McNemar tests to examine the pre- and posttest changes in the individual items on the three attitude scales. A series of analyses of covariance (ANCOVAs) were performed to compare intervention and control group participants on posttest scores of outcome measures for the continuous variables using the baseline score as a covariate. Type III sums of squares were employed as adjusted measures because the number of study participants in the intervention and control groups was not equal. The statistical package used to perform these analyses was SPSS for Windows, version 11.0 (2001).

Findings

The project has developed new instruments to assess social-cognitive aspects of exercise adherence for adults with cognitive impairments. The instruments have been found to be reliable and should be useful to others interested in studying exercise adherence in this population. Alpha reliabilities ranged from .66 to .91 and test-retest reliabilities ranged from .48 to .72. Also, the initial pre- and posttest analyses of these measures indicated that these measures were valid and sensitive to changes in treatments.

Results indicate that the key barriers to exercise for adults with I/DD were cost, being tired or bored by the exercise, and problems using equipment. About half of the individuals lacked confidence in their ability to

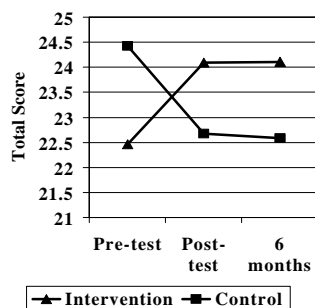
perform exercises. Specifically, *in comparison to the control group, participants in the intervention group* reported the following:

- decrease in barriers to exercise immediately after training ($p < .001$) and at 6 months ($p < .05$).
- improvement in their attitude toward exercise immediately after training ($p < .001$) and at 6 months ($p < .01$).
- improvement in their exercise knowledge immediately after training ($p < .01$) and at 6 months ($p < .001$).
- improvement in their social-environmental supports immediately after training ($p < .05$).
- improvement in their confidence to perform exercise immediately after training ($p < .001$) and at 6 months ($p < .05$).
- less depression 6 months after training ($p = .06$).
- increase in life satisfaction immediately after training ($p = .06$). Control participants reported a decrease in life satisfaction at post-test ($p < .05$).

The percent of participants in the intervention group who exercised increased 14% immediately after the intervention and 13% six months later. The intervention group improved in all outcome measures for cardiovascular fitness, strength, and body composition, whereas the control group showed no change or a slight improvement or decline.

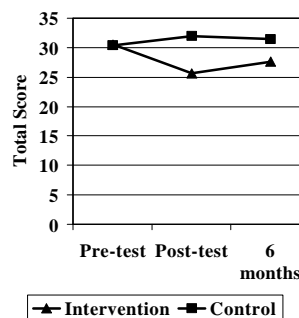
In general, the intervention group showed the greatest gains in upper and lower body strength,

Outcomes Expectations



Compared to the control group, participants in the intervention group reported improvement in their attitude toward exercise immediately after training ($p < .001$) and remained at 6 months after ($p < .01$).

Barriers to Exercise

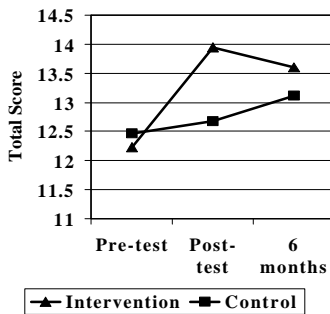


Compared to the control group, participants in the intervention group reported decrease in barriers to exercise immediately after training ($p < .001$) and 6 months after ($p < .05$).

followed by cardiovascular fitness (peak VO₂, time to exhaustion, workload). Improvements in cardiovascular fitness ranged from 14.1% in peak VO₂ to an increase of 27.1% in max workload. Improvements in strength ranged from 39% to 43% on both lower and upper body strength, respectively. The exercise program also had a small but significant effect on reducing body weight.

Women had significantly greater BMIs than did men; however, no other gender differences were found. Eighty-nine percent of participants were overweight or obese (18.8% were overweight and 70.8% were obese), 54% had large waist circumferences, and none met the current guidelines for fruit and vegetable intake. Mean concentrations for lipids and glucose, however, were within normal limits; and prevalence for hypertension, elevated lipids, and glucose were less than those for the general population of the United States.

Self-Efficacy

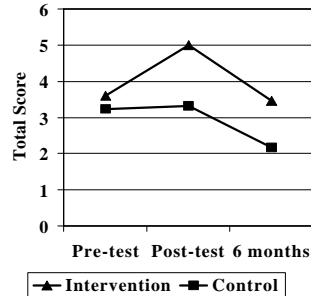


Compared to the control group, participants in the intervention group reported improvement in their confidence to perform exercise immediately after training ($p < .001$) and 6 months after training ($p < .05$).

Implications for Research and Practice

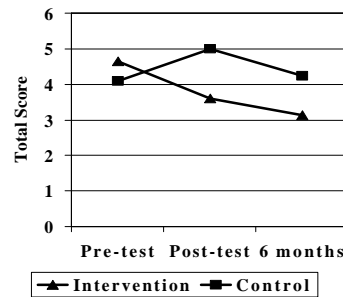
Overall, key short-term benefits for participants in the health promotion program included improvements in physiological and psychosocial health, such as, 1) greater life satisfaction; 2) increased exercise knowledge; 3) more positive attitudes toward exercise; 4) increased confidence in ability to exercise; 5) fewer barriers preventing participants from exercising; 6) improved cardiovascular fitness; and, 7) increased muscle strength and endurance. Key longer term (6

Social-Environmental Support



Compared to the control group, participants in the intervention group reported improvement in their social-environmental supports immediately after training ($p < .05$).

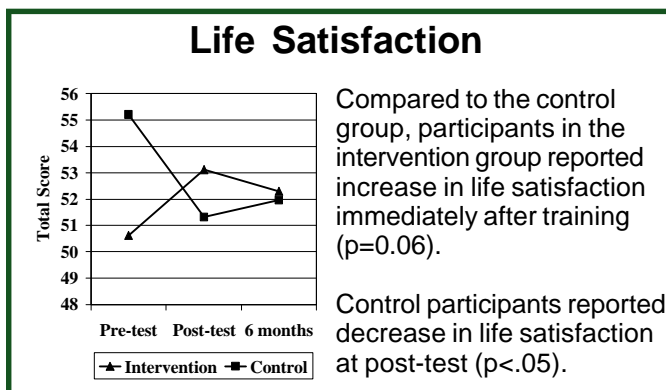
Depression



Compared to the control group, participants in the intervention group reported less depression 6 months after training ($p < .06$).

months) benefits include increased self-efficacy to exercise, increased exercise adherence, improved exercise knowledge, lower depression, and less barriers to exercise.

Additionally, our results demonstrate that adults with Down syndrome can understand health behavior education and benefit from an exercise program both immediately after training and 6 months after participation in the program. While the university-based program resulted in positive short-term outcomes, our results also support the need for community-based programs to maintain long-term adherence. Also, further investigation of long-term exercise participation in their daily life is needed.



Publications and Products

Heller, T., Hsieh, K. & Rimmer, J. (2004). Attitudinal and psychological outcomes of a fitness and health education program on adults with Down syndrome. *American Journal on Mental Retardation*, 109(2), 175-185.

Rimmer, J., Heller, T., Wang, E., & Valerio, I. (2004). Improvements in physical fitness in adults with Down syndrome. *American Journal on Mental Retardation*, 109(2), 165-174.

Braunschweig, C.L., Gomez, S., Sheean, P., Tomey, K.M., Rimmer, J.H., & Heller, T. (2004). High prevalence of obesity and low prevalence of cardiovascular and type 2 diabetes risk factors in adults with Down syndrome. *American Journal on Mental Retardation*, 109(2), 186-193.

Heller, T., Marks, B., & Ailey, S. (2004). *Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities* (2nd. ed.). Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago (UIC).

Hahn, J.E. & Marks, B. (Eds). (2003). Promoting Health across the Lifespan for Persons with Developmental Disabilities. Special Issue for *Nursing Clinics of North America*, 38(2).

Marks, B. & Heller, T. (2003). Bridging the equity gap: Health promotion for adults with developmental disabilities. *Nursing Clinics of North America* 38(2), 205-228.

Heller, T., Ying, H. S., Rimmer, J.H., & Marks, B. A. (2002). Determinants of exercise in adults with cerebral palsy. *Public Health Nursing*, 19(3),223-31.

Heller, T., Hsieh, K., & Rimmer, J. (2002). Barriers and supports for exercise participation among adults with Down syndrome. *Journal of Gerontological Social Work*, 38 ½, 161-178.

Heller, T. & Marks, B. (2002). Health promotion and women. In P.N. Walsh & T. Heller, T.(Eds.). *Health Promotion and Women with Intellectual Disabilities*. London: Blackwell Science Publishing, pp 170-189.

Ailey, S. H., Marks, B., & Heller, T. Evaluation of two self-report depression measures for adults with Down syndrome. *The NADD Bulletin* 2002; 5: 71-75.

Heller, T., Marks, B.A., & Ailey, S.H. (2001). *Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities*. Rehabilitation Research and Training Center on Aging with Developmental Disabilities, UIC.

