# UNIVERSITY OF OKLAHOMA

# COLLEGE OF EDUCATION

# THE EFFECTS OF A PROGRAM OF EXERCISE AND NUTRITION ON BODY COMPOSITION IN ADOLESCENTS AND YOUNG ADULTS WITH MODERATE COGNITIVE DISABILITIES: A DESCRIPTIVE STUDY

A Dissertation

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in partial fulfillment of the requirements for the

degree of

Doctor of Philosophy

By

LINDA L. ARNOLD Norman, Oklahoma 2004 UMI Number: 3152840

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## THE EFFECTS OF A PROGRAM OF EXERCISE AND NUTRITION ON BODY COMPOSITION IN ADOLESCENTS AND YOUNG ADULTS WITH MODERATE COGNITIVE DISABILITIES: A DESCRIPTIVE STUDY

# A Dissertation APPROVED FOR THE DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

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"To each is given a bag of tools, a shapeless mass, and a book of rules.

> And each will build, ere life is flown, a stumbling block or a stepping stone."

> > Alvin T. Smith

Life is the sum of experiences and reactions that are shaped by parents, family, and the people you come in contact with. I was blessed by parents, Alvin and Mildred Smith, who taught us good fortune was meant to be shared; while dedication, hard work, education, and the ability to adapt is required to change misfortune.

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Dedicated to

MICHAEL

AND

HIS FRIENDS

They have given me inspiration, genuine purpose, and

immeasurable joy.

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#### ABSTRACT

Over the past two decades, the prevalence of overweight and obese persons has increased dramatically and affects nearly 59 million U.S. citizens in all segments of the population. Obesity-related chronic health conditions account for 300,000 deaths annually, ranking second only to smoking as the leading preventable cause of morbidity and mortality. The most common health issue facing children is obesity, largely a result of inactivity and excessive food intake. Obesity's prevalence is rapidly increasing in minority populations that include the elderly and disabled.

Individuals with cognitive disabilities appear to age at a faster rate and experience chronic health problems earlier than the general population. The Surgeon General's 2000 Gap Report emphasized disparities in healthcare. The lifestyle of these individuals tends to be sedentary, with high incidence of obesity and low level of fitness. Only a handful of studies have investigated issues concerning health-related fitness in these individuals. Most were focused on examining the prevalence of obesity or behavioral interventions to ameliorate obesity.

Significant improvements in body fat percentage and basic health knowledge were obtained by participants (11) receiving an intervention of exercise training and instruction in nutrition and health concepts, when compared to the control group (7). Adolescents and young adults with moderate cognitive disabilities took part in this 12-week study with follow-up. Difference between measures used was not significant.

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#### CHAPTER I: INTRODUCTION

Health-related fitness in the United States has declined (Blair et al., 1989; Blair & Jackson, 2001; United States Department of Health and Human Services [USDHHS], 1996a, 1996b). Research findings have linked inactivity and sedentary lifestyle to chronic health problems (such as obesity, type II diabetes, coronary heart disease, cardiovascular disease, cancer, and osteoarthritis), poor quality of life, and related disability (Blair et al.; Blair, Cheng, & Holder, 2001; National Institute of Health [NIH], 1985, 1996; Pate et al., 1995; Torpy, 2003; World Cancer Research Fund [WCRF], 1997; World Health Organization [WHO], 1997). The growing prevalence of obesity (31%), diabetes (8%), metabolic syndromes (24%), and associated rising public health care costs have attracted the attention and concern of the American public, medical profession, media, policymakers, and researchers (Bonow & Eckel, 2003; USDHHS, 1992, 1996a, 1996b).

## Obesity's Contribution to Health

The important social health issue of being overweight or obese has reached epidemic proportions in the United States and worldwide (Cole, Bellizzi, Flegal & Dietz, 2000a, 2000b; Flegal, Carrol, Kuczmarski, & Johnson, 1998; Lewis, Jacobs, & McCreath, 2000; Mokdad et al., 1999, 2000). More than 50% of U.S. and British citizens are classified as overweight or obese. The exact incidence is clouded by the absence of a universally accepted definition, with prevalence dependent upon the

criterion used to define it (Cole et al.; Furnham & Manning, 1997; WHO, 1997, 1998). Although the definition of being overweight or obese varied in literature, it tended to include being 20% above an age-normed weight/height ratio (Dietz, 1987). The Centers for Disease Control and Prevention (CDC) and 1999-2000 National Health and Nutrition Examination Surveys (NHANES) based healthy body size levels on body mass index (BMI) with overweight defined as BMI  $\geq$  25 to 29.9 and obesity as BMI  $\geq$  30 (Bonow & Eckel, 2003; CDC, 2000; USDHHS, 1996). Accordingly, close to 59 million people in the U.S. population are considered obese and nearly two-thirds of Americans are considered overweight or obese (NIH, 1998). The health, medical, and financial costs of obesity to the U.S. population are far reaching (USDHHS). Beyond medical care costs, employment, poverty, and the overall lifestyle of obese individuals and their families are directly influenced.

All segments of the population are effected by overweight and obesity issues. Obesity affects approximately 33.3% of adults older than 20 and between 20% to 27% of children and adolescents in the U.S. (CDC, 1997, 2000; Kuczmarski, Johnson, Flegal, & Campbell, 1994). The number of overweight individuals in the United States is growing, with an increase of 27% seen in adolescents over the last 10 years (CDC; Troiano & Flegal, 1998). Obesity tends to run in families, with many obese children becoming obese adults (Craddack, 1978; Thompson, 1993). Genetic factors can make individuals susceptible to weight gain,

but the increased prevalence of obesity among the world's population has occurred too quickly for genetics to be the primary culprit (Cole et. al., 2000a, 2000b).

Obesity is considered preventable and has been linked to inactive, sedentary lifestyle and a diet of foods having low nutritional value (Adeyanju, 1990; Insel & Roth, 2004; NIH, 1998; Pi-Sunyer, 1993; WCRF, 1997). Inactivity's link to public health issues has gained attention and physical activity is seen as a means to potentially reduce health risk factors (USDHHS, 1996). Research informs us that overweight or obese individuals are at increased risk for developing chronic physical ailments such as type II diabetes, hypertension, coronary heart disease, ischemic stroke, colon cancer, postmenopausal breast cancer, endometrial cancer, gall bladder disease, osteoarthritis, and obstructive sleep apnea (NIH; Stunkard, 1958; Stunkard & Sorensen, 1993; USDHHS).

During the 1980's, research focus on adult health began a shift toward lifelong health-related fitness beginning during childhood (Simons-Morton, Parcel, O'Hara, Blair, & Pate, 1988). Chronic health problems were hypothesized to begin in childhood and escape detection until later in life (American College of Sports Medicine [ACSM], 1991, 1995, 1998; Corbin, 2002; Corbin & Lindsey, 1997; Simons-Morton, O'Hara, & Simons-Morton, 1986). A reported 20-year trend of increased body fat in children within the U.S. that might effect long-term health

and shorten lifespan supported the hypothesis (Corbin & Lindsey; Ross, Pate, Lohman, & Christenson, 1987). Findings that certain chronic diseases once reserved for adults (such as diabetes II) had seen their onset in children also supported the hypothesis (Eichstaedt & Lavay, 1992; Strauss & Pollack, 2001, 2002; Troiano & Flegal, 1998).

Three national government research studies conducted in the 1980's (the National Children and Youth Fitness Studies I and II in 1985 and 1987, and the President's Council on Physical Fitness and Sports School Population Fitness Survey, 1985) confirmed the lack of fitness among America's youth (Ross et al., 1987; Seamon, 1999). Prevention of overweight and obesity has been the underlying goal of many government programs; however, sole concentration of efforts on prevention would overlook the plight of millions of persons that suffer from chronic illnesses linked to obesity (CDC, 2002, 2004). Many children included in early research identifying the growing trend toward U.S. childhood obesity are now adolescents and young adults, still in need of treatment for obesity and associated diseases.

# Factors Contributing to Obesity

A recent awareness of health issues that can be addressed through exercise and nutrition is emerging. Levels of physical activity and nutritional habits have been demonstrated as the most influential determinants of obesity for the general population (Insel & Roth, 2004). Communities are often not organized with fitness in mind; few sidewalks

are available to promote walking and bicycle riding (Chessher, 1999). Time spent in sedentary activities (such as watching television, playing video games, or engaging in computer activities) has left little time for exercise or moderately vigorous activities (Shannon, 1985; Vandercook, 1991). Inactivity or participation in activities at a level too low to effect fitness (inadequate frequency, duration, or intensity) is a frequent problem [Adeyanju, 1999; Insel & Roth; Seamon, 2001). Public school physical education and health programs are not widely available (Insel & Roth; Seamon). Some students do not demonstrate the motivation to be physically fit, their attitudes and actions are inconsistent with a desire to be fit (Seamon). Motivation and physical activity are thought to be related (Roberts, 2001).

Children's poor eating habits were partially attributed to lack of appropriate lifestyle role models in families with two working parents that made poor nutritional choices and consumed too much fast food (French, Story, & Jeffrey, 2001; Hill & Peters, 1998; Jacobson & Fritschner, 1991). Restauranteurs have stated that people talk health, but they "buy taste" and fast food in oversized portions (French et al.; Hill & Peters; Jacobson & Fritschner). Lack of nutritious school cafeteria menu choices and the combined presence of drink and snack machines have affected the weight levels of students (Guthrie & Morton, 2000; Jacobson & Fritschner).

Socioeconomic status often influences health care and community

access (Dietz, 1987; Furnham & Manning, 1997). Literacy, age, and family income are strong predictors of health (CDC, 1997, 2000, 2004; Uffen, 2000; United Nations Education, Scientific, and Cultural Organization, 1989, 1991). Although mandated by law, it cannot be assumed that all children are taught to read (Boe, Cook, Bobbit, & Terhanian, 1998; Center on Education Policy, 2004; Schumm & Vaughn, 1991; Villa, Thousand, Meyers, & Nevin, 1996; Whinnery, Fuchs, & Fuchs, 1991). Appropriate basic health material with basic nutrition information that is factual, simple to understand, and fun, is not available at varying literacy levels. Most health-care materials are written at or above a tenth grade reading level; and most Americans read at an eighth- or ninth grade level (National Reading Panel, 1999). Individuals with disabilities are included in the population's 20% that read at or below the fifth grade level. Literacy issues can affect taking medications appropriately and understanding healthcare instructions (CDC; Katims, 2000; Turnbull, Turnbull, Shank, & Smith, 2004; Uffen).

# Health Interventions

Health trends and promising research prompted U.S. Surgeon Generals to issue national reports that stressed the importance of physical fitness and promoted increased exercise in children and youth (USDHHS, 1980, 1991, 1992, 1995, 1996, 2002). The suggested combination of increased physical activity and healthy nutritional choices beginning in childhood, could contribute to health-related fitness

and better long term individual health outcomes (Corbin & Lindsey, 1997; Lancioni, Oliva, Bracalenete, & ten Hoopen, 1996; Liberman, 2002; Liberman, Butcher, & Moak, 2001; USDHHS). Historically, programs implemented to increase physical fitness in children have achieved some success (Butcher et al., 1988; Duncan, Boyce, Itami, & Paffenbarger, 1983; President's Council on Physical Fitness, 1985, 2004). Many government reports were focused on the physical activity needs of the general population while children with disabilities, who might gain the same benefits from physical activity, have been ignored (Lieberman).

Current health education is based on the energy balance equation with physical activity and good nutrition required for health and fitness (Insel & Roth, 2004). It appears that quality of life and chances for longevity could be improved while reducing premature death and related disability due to preventable health problems associated with obesity (USDHHS, 1995). Lifestyle changes that include increased regular activity and exercise training, can increase muscle mass. Better nutritional habits can positively affect excess fat. The combination of exercise and nutrition could improve body composition and healthrelated fitness (Insel & Roth; USDHHS). Ziegler (1993) stated that addressing individual physiological needs and interests in physical activities was necessary to form life long healthy lifestyle habits. It has been recommended that individuals aged 2 years and older participate in a minimum of 20 minutes of moderately intense activity everyday

(USDHHS, 1996).

Health Status of Individuals with Disabilities

Nearly 15% of children (infants through adolescents) and most individuals as they age, are affected by disability (Turnbull et al., 2004). Individuals with cognitive disabilities were demographically identified by epidemiological surveys as a population subset with chronic health issues needing intervention (Special Olympics, 2001; USDHHS, 1995, 2002). A greater risk of developing health issues exists in persons with disabilities than the general population (Gillespie, 2003; Horowitz et al., 2000). Research revealed that people with cognitive disabilities experience more chronic health problems, receive inadequate health care, and achieve poorer outcomes when compared with their nondisabled peers (Gillespie; Horowitz et al.; Special Olympics; USDHHS, 1996, 2002).

Obesity is prevalent in an inordinate percentage of persons with disabilities (Burkhart, Fox, & Rotatori, 1985; Eichstaedt & Lavay, 1992; Gunay-Aygun, Cassidy, & Nicholls, 1997; Kelly, Rimmer, & Ness, 1986; Pitetti, Rimmer, & Fernhall, 1993). Characteristics of the primary disorder (such as hypotonia, short stature, hypothyroidism, and hyperphagia) can contribute to intrinsic obesity. Unhealthy diet, inactivity, and lack of stimulation can be reflected as constitutional obesity. Persons with etiologies including genetic anomalies (such as Down syndrome, Prader-Willi syndrome, and fragile X syndrome) display

a greater tendency toward obesity (de Vries et al., 1993; Gunay-Aygun, Cassidy, & Nicholls). Individuals with mild to moderate cognitive disabilities have been found to possess lower levels of health-related fitness and display obesity more frequently than the general population (Bell & Bhate, 1992; Burkhart, Fox, & Rotatori; Eichstaedt & Lavay; Jackson & Thorbecke, 1982; Nordgren, 1970, 1971; Rimmer, Braddock, & Fujiura, 1993; Simila & Niskanen, 1991; Special Olympics, 2001; Staugaitis, 1978; USDHHS, 2004). Body composition research revealed that disproportionate numbers of persons with mental retardation possess unhealthy levels of body fat that are known to increase the opportunity for early onset of hypertension and type II diabetes mellitus (Burkhart, Fox, & Rotatori; Eichstaedt & Lavay; Jackson & Thorbecke; Pitetti, Rimmer, & Fernhall; Staugaitis). Research indicated that individuals with cognitive disabilities exhibit a high risk for developing cardiovascular disease, which is the leading cause of death in the U.S. (Carter & Jancar, 1983; Gibson, 1997; Rimmer et al., 1992).

The fitness levels of persons with disabilities have been found to be lower than that of their nondisabled peers (Coleman, Ayoub, & Friedrick, 1976; Burkhart, Fox, & Rotatori, 1985; Eichstaedt & Lavay, 1992; Jackson & Thorbecke, 1982; Maksud & Hamilton, 1974; Pitetti, Rimmer, & Fernhall, 1993; Staugaitis, 1978). Persons with disabilities tend to lead sedentary lifestyles with less frequent participation in exercise and athletic pursuits than persons without cognitive disabilities (Baer & Wolf,

1970). An overwhelming need exists to develop techniques that would reduce the gap in health-related fitness between persons with and without disabilities (Horowitz et al., 2000; Special Olympics, 2001; USDHHS, 2002, 2004). Age-related fitness changes indicate that response to exercise is similar in persons with and without disabilities, although movement needs may differ due to lower initial fitness (Rimmer, 1999; Seamon, 1999).

#### Factors Contributing to Obesity in Persons with Disabilities

It has been suggested that the lifestyle of U.S. individuals with cognitive disabilities might account for many chronic illnesses (Frey & Rimmer, 1995). Researchers alluded to the deinstitutionalization trend of the late 1960's as the primary cause of poor health and health care disparity among persons with disabilities and the general population (Horowitz et al., 2000; Minihan, 1986; U.S. Surgeon General's Report, 2002). Living arrangement has been shown to influence the occurrence of obesity in persons with cognitive disabilities (Pitetti & Campbell, 1991; Rimmer, Braddock, Fujiura, 1993). Researchers have rationalized that individuals with cognitive disabilities were placed in unfamiliar community living arrangements and overwhelming circumstances (work, housing, social, leisure/recreational needs, medical care responsibilities) they were unprepared to handle without support (Horowitz et al.). The added element of self-determined choice provided persons with cognitive disabilities opportunities to make the same poor health, nutrition, and

fitness choices demonstrated by the general population (Wehmeyer, 1994).

Research indicates that individuals with disabilities are affected by the same factors that contribute to sedentary lifestyle and poor healthrelated fitness problems experienced in the general population (Frey & Rimmer, 1995). For individuals with disabilities, factors contributing to obesity begin with those previously listed and grow from there.

A unique set of barriers for persons with disabilities is presented and supported by an almost 50-year recognition of the unchanged disparity in motor abilities and fitness levels between individuals with and without disabilities (Francis & Rarick, 1959). As researchers have noted, awareness and training have not kept pace with the growing need and numbers of persons with disabilities in the community that are graying along side the population without disabilities (Flexer, Simmons, Luft, & Baer, 2001; Haring, 1987; Haring, Lovett, & Smith, 1990; Scuccimarra & Spence, 1990; Wehman, Kregel, & Seyfarth, 1985).

Many individuals with cognitive disabilities do not know the rationale for being healthy and are unaware of the probable chronic illnesses that lead to long-term poor health outcomes of poor nutrition and inactivity (Heward & Orlansky, 1992; Horowitz et al., 2000; Sherrill, 1998a, 1998b; Special Olympics, 2001, 2004; USDHHS, 2002). The passage of public law 94-142 mandated an outcome-oriented transition process to develop and access educational programs and community

experiences that would prepare individuals with disabilities to successfully navigate life domains after completion of secondary school. Post-secondary outcome studies of individuals with cognitive disabilities have historically found them especially ill prepared to handle life's challenges, including health and fitness issues (Flexer et al., 2001; Haring, 1987; Haring, Lovett, & Smith, 1990; Scuccimarra & Spence, 1990; Wehman, Kregel, & Seyfarth, 1985). Literature suggested that many persons with cognitive disabilities live structured, sedentary lives at or below poverty level, lacking needed support, ability, or opportunity to access community-based environments (McDonnell et al., 1993; Pitetti, Rimmer, & Fernhall, 1993; Turnbull et al., 2004).

Health curricula in public schools, for many individuals with cognitive disabilities, do not address specific diet and activity patterns needed to maintain or improve health and fitness (Heward & Orlansky, 1992; Horowitz et al., 2000; Special Olympics, 2001, 2004; USDHHS, 2002). The health-related fitness of individuals with cognitive disabilities is affected by limited access to recreation, leisure sports, and exercise activities; paired with transportation problems, and limited knowledge of programs, rules, and procedures (Flexer et al., 2001; Haring, 1987; Haring, Lovett, & Smith, 1990; Scuccimarra & Spence, 1990; Special Olympics, 2004; Wehman, Kregel, & Seyfarth, 1985).

Exercise training (rationale, routines, and assistive exercise equipment), physical activity, and sports are not provided by general

public school physical education or community recreation programs for individuals with cognitive disabilities (Sherrill, 1998a, 1998b). Many of the sports activities offered to children through young adults with cognitive disabilities in public schools are Special Olympics activities, noninclusive, short term, and not selected by students (Modell & Valdez, 2002). Even though there are a wide variety of sports sponsored by Special Olympics, not all are offered in every state or region (Special Olympics of Oklahoma, 2004).

Communication, adaptive behavior deficits, low motor skills, and attitudinal concepts pose significant barriers to inclusion in activities (Sherrill, 1998a, 1998b). Lack of motivation to participate in community activities was cited as a problem for individuals with cognitive disabilities when learned-helplessness (repeated failure limits motivation) might be a more accurate determinant (Turnbull et al., 2004). Inactivity has been connected to issues concerning lack of opportunity and motivation to participate socially in group or individual exercise activities (Kozub & Porretta, 1998). Some inactivity patterns of persons with cognitive disabilities can be explained by family interactions, rather than by motivation alone (Fiorini, Stanton, & Reid, 1996; Kozub, 2001, 2003). This set of circumstances could influence health-related fitness problems that might be ameliorated with opportunities linked to vigorous activity, and basic health and nutrition education.

Individuals with cognitive and physical disabilities experience

difficulties obtaining appropriate medical and health-related care (Heward & Orlansky; 1992; Horowitz et al., 2000). Refusal to accept Medicaid payments is often exacerbated by doctors and medical personnel who do not understand the behavioral and intellectual characteristics of individuals with mental retardation needed to with work them (Horowitz et al.). Partially because of communication problems, adaptive behavior deficits, and attitudinal barriers, little opportunity is given for individuals with cognitive disabilities to provide input or share perceptions associated with their health-related issues (Wilson & Haire, 1990). Health and nutrition education for this population, physicians, and caretakers is greatly needed. Needs for improved fitness and healthier lifestyles will increase if specific interventions are not implemented.

## Statement of Need

Minimally, strides must be made to develop and implement a program of health and nutrition education, combined with vigorous activity, for individuals with cognitive disabilities. Ideally, a preventative health program should be created utilizing community health clubs and exercise facilities, with payment vouchers provided by insurance or government agencies (such as Medicaid). A program to gather information on the health, activity needs, and perceptions of individuals with disabilities and their parents or caregivers, should be developed and important findings implemented by improved programs. Of utmost

importance, is the development of a program to orient and train preservice and current professionals (medical, health, nutrition, and exercise) in basic characteristics, behaviors, and communication techniques to work with persons experiencing cognitive and physical disabilities. Training, follow-up, and authentic interaction with persons having disabilities, should be required at regular intervals.

## Significance of Current Research

Obesity is a chronic problem linked to many diseases and associated with poor health-related fitness. Current research has identified factors that contribute to sedentary lifestyle and chronic poor health-related fitness experienced by young people universally. Individuals with disabilities experience the same factors that lead to unhealthy lifestyles in the general population, as well as many additional barriers attributed to their clinical disabilities. Research into controlling weight through behavior therapy and caloric restriction has shown varied short-term success, with ineffective long-term results.

The review of literature focused on the health-related fitness of individuals with cognitive disabilities included these major areas: (a) prevalence of obesity and overweight (Fox & Rotatori, 1982; Kelly, Rimmer, & Ness, 1986; Kreze, Zelina, Juhas, & Garbara, 1974; Polednak & Auliffe, 1976; Simila & Niskanen, 1991); (b) lag in motor development and lower fitness levels (Campbell, 1973; Cratty 1967, 1969; Gillespie, 2003); (c) behavior therapy weight loss studies (Cottrell, 1985; Foreyt &

Parks, 1975; Fox, Haniotes, & Rotatori, 1984; Fox, Rosenberg, & Rotatori, 1985; Heiman, 1978; Jackson & Thorbecke, 1982; Joachim, 1977; Joachim & Korboot, 1975; McCarran & Andrasik, 1990; Norvell & Ahern, 1987); (d) studies focused on cardiovascular fitness and muscular endurance; and (e) capability to learn leisure and recreational skills and activities in segregated and integrated communities (Baer & Wolfe, 1970; Vandercook, 1991).

A paucity of intervention studies has explored the effects of combined exercise and nutrition on persons with cognitive disabilities (Chanias, Reid, & Hooper, 1998; Pitetti, Rimmer, & Fernhall, 1993). Few validated health-related fitness interventions exist for persons with moderate cognitive disabilities (Chanias, Reid, & Hooper). Exercise as a strategy for weight loss has seldom been studied; improvement of health was not a focus (Croce, 1990; Fisher, 1986; Pitetti & Tan, 1990, 1991; Ross, 1975; Skrobak-Kaczynski & Vavik, 1980). Studies often were not n conducted in community settings. There is a dearth of appropriate basic health, nutrition, and exerencise intervention material for individuals with cognitive disabilities. Research has been inconclusive explaining reasons for the higher prevalence of overweight and obesity exhibited by individuals having moderate cognitive disabilities, compared to persons with mild, and severe to profound disabilities. Individuals with moderate cognitive disabilities are a low-incidence population in need of study. Possible links between obesity and syndromes or clinical diagnosis need

further exploration. Health-related fitness studies into body composition, flexibility, and muscular strength should be explored further. Lifestyle patterns of individuals with cognitive disabilities have not been studied. No research study involved participants with cognitive disabilities that had self-identified a weight concern. Perspectives of persons with cognitive disabilities and their parents, regarding the effectiveness of health-related fitness interventions, have not received sufficient interest. Interventions studied were often too difficult for individuals with cognitive disabilities to continue alone, if desired.

Methodological problems exist in studies of health-related fitness focused on overweight and obesity in individuals experiencing cognitive disabilities, which have largely failed to demonstrate long-term success: (a) most prevalence and intervention studies have included weight rather than body composition as the targeted dependent variable; (b) measures were inconsistent among studies and had not kept pace with current practice; (c) criterion for defining weight level varied between studies; (d) participant description and procedural detail was insufficient to systematically replicate or generalize; (e) control groups were infrequently used, possibly due to small sample sizes; and (f) few studies included long-term follow-up.

## Statement of Problem

Adolescents and young adults with moderate cognitive disabilities have displayed lower levels of health-related fitness and higher levels of

obesity than their nondisabled peers, which may be related to degree of retardation, gender, age, physical activity, or variations in nutrition issues (Burkhart, Fox, & Rotatori, 1985; Horowitz et al., 2000; Fox & Rotatori, 1982). A specific program to measure and improve the body composition element of health-related fitness in individuals with moderate cognitive disabilities was not available. No empirical knowledge base on fitness and nutrition for adolescents and young adults with disabilities existed, or descriptions of perspectives and concerns on this topic, from these individuals or their parents. Only anecdotal notes existed to document concerns regarding their healthrelated fitness.

#### Statement of Research Purpose

The purpose of this research was to determine the effects of a program of combined exercise training and basic knowledge of health and nutrition concepts, on the body composition and perspectives of adolescents and young adults with moderate cognitive disabilities, and their parents.

### Rationale for the Research

Introduction of a voluntary structured program of exercise with basic health and nutrition instruction, to a group of adolescents and young adults with moderate cognitive disabilities, is expected to affect body composition, promote awareness, and practice of program elements. Perceptions about taking part in a voluntary program of

fitness will be gathered from participants and their parents. Study results will add to the empirical knowledge base. An improved quality of life for participants should result with continued activity and better nutritional choices.

# Statement of the Research Questions

The following questions will be addressed through the participation of adolescent and young adults with moderate cognitive disabilities in a voluntary program of combined exercise training and basic health and nutrition instruction called Healthy Choices:

- Will a program of exercise and basic nutrition and health education have an effect on the body composition of adolescents and young adults with moderate cognitive disabilities?
- 2. Will a program of exercise and basic nutrition and health education have an effect on the body weight of adolescents and young adults with moderate cognitive disabilities?
- 3. Will a correlation exist between field methods selected to estimate body composition in participants?
- 4. Will a program of exercise and basic nutrition and health education have an effect on the knowledge of these concepts in adolescents and young adults with moderate cognitive disabilities?
- 5. From the perspective of participants and their parents, did a program of exercise and basic nutrition and health education have an effect on them?

#### Summary

The health-related fitness of adolescents and young adults with cognitive disabilities is lower than for their nondisabled peers. The prevalence of obesity is greater in adolescents and young adults with mild to moderate cognitive disabilities than their peers. Body composition is the component of health-related fitness that includes body fat percentage and dispersion. A need exists to describe the effects of basic nutrition/health education and exercise on the body composition of adolescents and young adults with moderate cognitive disabilities.

## Definition of Terms

The following conceptual definitions will be used in this study.

Adaptive behavior. Individual skills and behaviors that meet social, conceptual, and practical expectations of society and the environment. The areas included are central to life functions: communication, selfcare, home-living and life-skills, social skills, community use, selfdirection, health and safety, functional academics, leisure, and work. Grossman (1983) defined adaptive behavior deficits as the degree of ineffectiveness that a person fails to meet society's expectations of personal independence and responsibility for their age and cultural group.

*Adipose tissue*. Excess food consumed (energy) that is stored as subcutaneous fat tissue.

Affective domain. The behavior area that includes feelings,

attitudes, intentions, values, interests, and desires (such as self-concept, body-image, social competency, inclusion, and fun/mental health (Sherrill, 1998b).

Anthropometric measurement. A body measurement taken externally (such as weight, height, circumference [girth], and skinfold thickness).

*Atherosclerotic diseases.* Related to heart attack and stroke, chronic severe cardiovascular problems.

Behavior domains. Affective, cognitive, and psychomotor areas.

*Body composition.* The component of health-related fitness focused on the body's make-up and expressed by relative percentage. The two component model includes fat-free body mass (such as muscle, bone, and organs) and the fat mass (adipose tissue). The composition of the body is often reported as body mass index (BMI).

*Body density.* Refers to specific components (such as bone, muscle, and body fat) of the body usually determined through laboratory methods (such as hydrostatic weighing and dual energy x-ray absorption [DEXA]). Few body density studies have been conducted with individuals having diagnosed disabilities.

*Body fat.* Body fat contributes no strength advantage and limits endurance, speed, and movement through space. There are two types of body fat: (a) essential fat [necessary for buoyancy, shock absorption, temperature, thermal insulation, and essential body nutrient regulation;

and (b) nonessential fat [excess adipose tissue accumulated as a result of more calories consumed than expended, causing over-fatness].

*Body mass index (BMI).* A screening, rather than diagnostic, tool used to indicate body weight adjusted for height to estimate body fatness relative to standardized height-weight tables. BMI is calculated by converting inches and pounds to meters and kilograms. Body fatness BMI guidelines have high correlations (0.7 and 0.8) to body density measures of body fat (Dietz, 1987). Relative to body size or weight based BMI, adults aged 20 and older are put into one of five categories (underweight, normal, overweight (25-29.9), obese (30-39.9), and superobese (also called extreme and morbid) (40 or higher).

BMI's comparison of the proportion of fat to lean body mass expression of obesity has the following limitations: (a) over-estimation of body fat and identification as being overweight, as a result of large muscle mass developed through regular exercise; and (b) underestimation of body fat resulting from loss of muscle mass, which occurs with aging, inactivity, and illness.

Body type. Body size, build, and composition.

*Cardiovascular disease (CVD).* Diseases that affect the heart and vascular passageways (such as atherosclerosis, arteriosclerosis, stroke and hypertension [high blood pressure]).

*Cognitive disability.* The term used throughout this paper when referring to individuals experiencing *mental retardation*.

*Cognitive domain.* Behavior domain including intellectual skills (using perceptual-motor function) to think and move creatively in order to learn necessary play skills, game behaviors, sport rules, and strategies (Sherrill, 1998b).

*Coronary heart disease*. Diseases affecting the heart (coronary occlusion, angina pectoris, and congestive heart failure).

*Disability.* The loss or reduction of functional ability and/or activity (WHO, 1980). Insurance loss reduction stipulates a difference exists between individuals with this type disability and persons with congenital disabilities who are born with less than normal abilities.

*Exercise*. A subset of physical activity that is planned, structured, and repetitive. Often maintenance or improvement of physical fitness is the final or intermediate objective of exercise.

*Fitness*. Two types of body fitness exist: (a) physical fitness, and (b) motor fitness (Sherrill, 1998a).

*Flexibility*. The functional range of motion about a joint that is affected by muscle length, joint structure, and other factors.

*Handicap.* A condition produced by societal and environmental barriers (WHO, 1980).

*Health-related physical fitness*. The components of physical fitness having a direct relationship to good health (cardiorespiratory endurance, body composition, flexibility, and muscular strength and endurance).

Healthy Choices. The combined intervention of basic nutrition and

health instruction with exercise training used in this research study.

Height and weight BMI table. Standardized measures of weight for height calculated to represent BMI in table form, historically normed on the general population. Many tables are separated by gender and age. Limitations include: (a) over-estimation of body fat percentage in a person with large muscle mass that could be interpreted as being overweight (resulting from exercise); (b) under-estimation of body fat due to lost muscle mass that could be interpreted as being underweight (could result from aging, inactivity, or illness).

Hyperphagia. Eating too much.

*Hypothalamus.* The portion of the brain that regulates many body functions, such as temperature.

Hypotonia. Low tension or tone in muscles.

*Impairment.* Any disturbance of, or interference with the normal structure and function of the body (WHO, 1980).

*Life domains*. Functional activities of life grouped into these areas: applied money concepts, leisure and recreation activities, health and safety, and career education.

*Mental retardation.* Referred to as *cognitive disability* in this study. The three elements are necessary for the diagnosis: (a) significant subaverage intelligence measured by a standardized test of intelligence (usually two standard deviations below average IQ; 70 or below); (b) coexisting difficulties in adaptive behavior; and (c) occurrence by age 18.

*Motor fitness.* Skill related ability often associated with sports. Components include agility, balance, coordination, speed, power, and reaction time.

*Muscular endurance*. The ability of a muscle or muscle group to repeatedly contract at some sub-maximal level (such as with swimming, or arm curls in an exercise set).

*Muscular strength.* The ability of a muscle or muscle group to exert a force during a single, maximal contraction (such as swinging a golf club to hit a ball).

*Nutrition.* The study of nutrition includes assessing food intake and its content (such as calories, vitamins, minerals, carbohydrates, fats) as well as metabolism and the efficient use of energy generated.

*Obesity.* A condition described by an excessively large percentage of fat tissue stored in the body (Garrow, 1974, 1986, 1994). Two types of obesity are: (a) constitutional obesity, due to external factors such as inactivity or food intake; (b) intrinsic obesity, due to inborn nature toward excess fat storage, not dependent on external circumstances.

*Overfat.* An excess of body fat. Level of body fat is considered more important than body weight in determining health and wellness.

*Physical activity.* Bodily movements (such as occupational, sports, conditioning, and household) produced by skeletal muscles that result in energy expenditure that can be measured by kilocalories.

Physical education. School curriculum of physical activities (sports

and exercise conditioning) and health education designed to help each student reach their full intellectual, physical, and social potential.

*Physical fitness.* Fitness most related to health (cardio [respiratory and vascular] endurance, muscular strength, muscular endurance, flexibility, and body composition). This set of attributes a person has or achieves is related to the ability to perform or adapt to the demands and stress of physical effort or activity at a moderate to vigorous level without becoming overly tired (Caspersen, Powell, & Christenson, 1985; Insel & Roth, 2004; Pate, 1995). All activities of life are considered (such as employment, domestic chores, structured sports and exercise). Attitudes (self-confidence, self-determination, and self-esteem), beliefs, and intentions have an affect on starting and maintaining fitness practices.

*Proxy.* A person empowered to act for, or in conjunction with, another. Individuals with cognitive disabilities have demonstrated the ability to better express their opinions, perspectives, and verbal responses to questions, when proxies are used, if needed, in research studies (Agnes & Guralnik, 2001). To ensure key respondent's responses are valid and reliable, they must have been acquainted with the proxy for an extended period, and not be unduly pressured or influenced. Teachers and unfamiliar persons are not reliable proxies.

*Psychomotor domain.* Behavior area including sensorimotor function, physical and motor fitness, motor and skill patterns, skill/participation habits in sports, dance and aquatics (Sherrill, 1998b).

### CHAPTER 2: REVIEW OF THE LITERATURE

### Overview

Being overweight or obese is a chronic public health issue that has reached epidemic proportions worldwide. All segments of the population are affected (Flegal, 1999; Flegal, Carroll, Kuczmarski, & Johnson, 1998; Flegal, Carroll, Ogden, & Johnson, 2000; Flegal, Kuczmarski, & Johnson, 1998; Kuczmarski, Flegal, Campbell, & Johnson, 1994; Lewis, Jacobs, & McCreath, 2001; Mokdad et al., 1999, 2000). Obesity is regarded as preventable and is in need of a multifaceted approach for prevention or amelioration (Cole et al., 2000a, 2000b; Horowitz et al., 2000; Strauss & Pollock, 2001, 2002; WCRF, 1997). Weight-related conditions rank only second to smoking as the leading preventable cause of morbidity and mortality, accounting for 300,000 deaths annually (McGinnis & Foege, 1993). More than 50% of U.S. and British citizens are overweight or obese (Cole et al.).

Following 1999-2000 NHANES, it was estimated that nearly 59 million people in the U.S. were considered obese (BMI 30+) or overweight (BMI 25-29.9). A substantial increase in the prevalence of obesity has occurred over the last 2 decades (Flegal, 1999; Flegal et al. 2002; Flegal et al., 1998; Mokdad, Bowman, Ford et al., 2001; Mokdad, Serdula, Dietz et al., 1999; Mokdad, Serdula, Dietz, Bowman et al., 2000). Being overweight is the most common health problem facing U.S. children and its prevalence is rapidly increasing among minority populations, which

includes the elderly and persons with disabilities (Flegal & Troiano, 2000; Hedley et al., 2004; Ogden et al., 2002; Ogden, Troiano et al., 1997; Pi-Sunyer, 1993; Power, Lake, & Cole, 1997; Strauss & Pollock, 2001, 2002; Troiano & Flegal, 1998; Troiano, Flegal, Kuczmarski, Campbell, & Johnson, 1995). NHANES 1999-2002 used height and weight measurements to derive BMIs for the sample (U.S. persons over age 2, not institutionalized), finding that 16% of U.S. children and adolescents were overweight (defined as at or above the 95th percentile) (Flegal; Flegal & Troiano; Ogden et al.; Ogden & Troiano et al.). A 45% increase in the prevalence of being overweight was indicated since the 11% reported by NHANES III (1988-1994) (Flegal; Hedley et al.; National Center for Health Statistics [NCHS], 2004a, 2004b; Ogden et al.). The 1988-1994 NCHS (1994a, 1994b, 2004a, 2004b) reported a 16% increase in U.S. adults (age 20+) estimated to be overweight or obese (65%) over NHANES III age-adjusted estimates (Flegal et al., 2002).

Obesity in the state of Oklahoma (22.9%  $\pm$  1.2), Oklahoma county (22.2%  $\pm$  2.9), and metropolitan Oklahoma City (21.7%  $\pm$  2.2) survey areas have mirrored the national trend toward increased adult obesity (22.2%); no figures for overweight persons were reported (Behavioral Risk Factor Surveillance System [SMART BRFSS], 2004; National Center for Chronic Disease Prevention and Health Promotion [NCCDPHP], 2004). The prevalence of obese adults in Oklahoma climbed dramatically from 1991 (11%) to 2003 (over 20%) (BRFSS, 2004).

An alternative perspective for coping with being overweight emerged and espoused size acceptance, rather than size reduction (Hebl, 1997). While self-acceptance is worthwhile, research informs that overweight or obese individuals are at increased risk for developing physical ailments (Garrow, 1994). Chronic diseases linked to obesity include cardiovascular disease, coronary heart disease, type II diabetes, gall bladder disease, ischemic stroke, colon cancer, post-menopausal breast cancer, endometrial cancer, obstructive sleep apnea, psychosocial disability, hypertension, and osteoarthritis and muscular-skeletal disorders. Lifestyle greatly affects the impact of excess weight on health. The leading cause of U.S. mortality is acknowledged as cardiovascular disease for all individuals (NCHS, 1994a, 1994b; National Heart Lung and Blood Institute [NHLBI], 1998a, 1998b, 1998c, 2000, 2004; NIH, 1996). Diabetes is a disease often linked to obesity and affects 6.7% of persons nationally and in Oklahoma (6.7% + 0.6). The prevalence of diabetes is slightly lower in metropolitan Oklahoma City (5.9% + 1.2) and Oklahoma county (5.8% + 1.4) (BRFSS, 2004).

Research informs that sedentary, inactive lifestyle and poor nutrition are the major causes of overweight problems (Insel & Roth, 2004). Individuals may be able to control lifestyle factors that contribute to obesity and ultimately affect their health (such as physical activity, eating habits, and serum cholesterol) (Adeyanju, 1990; CDC, 2004a,

Factors Contributing To Overweight and Obesity

2004b, 2004c, 2004d; Garrow, 1986, 1994; NIH, 1998; Sherrill, 1998a, 1998b; Stunkard, 1958; Stunkard & Penick, 1979; Stunkard & Sorensen, 1993; Van Itallie, 1979, 1985; Van Itallie & Abraham, 1985). Children and adolescents that are overweight or obese are likely to continue that status into adulthood, with higher risk of developing associated chronic diseases at a younger age (Casperson, Powell, & Christenson, 1985; Finney & Gerken, 2003; Flegal & Troiano, 2000; NCHS, 1994a, 1994b; Strauss & Pollock, 2001, 2002).

The encroachment of fast food and soft drinks into our school cafeterias (Appendix A) has contributed to the increased number of children, adolescents, and young adults with weight problems (Guthrie & Morton, 2000; Ludwig, Peterson, & Gortmaker, 2001). The first law requiring physical education (PE) in American schools was passed in 1866 and proposed programs to improve health, stamina, and strength for the masses (Corbin, 2002; Singer, 1976). A 50% decrease in student participation in daily PE programs has occurred over the last decade, partially due to slashed budgets in many school districts (Glanz, Basil, Malbach, Goldberg, & Snyder, 1998; Sarasan, 1982; USDHHS, 2000). A recent survey revealed the top 5 PE activities in middle and high school were team sports (Simons-Morton, Eitel, & Small, 1999). Currently, only 25% of high school students attend daily PE classes, with elite athletes comprising much of that percentage (CDC, 2000, 2004; Gehring, 2002; Ryckman & Hamel, 1993). The most popular three physical activities in

adulthood are individual sports (USDHHS, 1996a, 1996b). The PE philosophy has been reshaped to reflect growing health concerns with daily activity encouraged and the need for sensible nutrition stressed as part of a healthy lifestyle (Anderson & Jakicic, 2003; Chessher, 1999; Corbin, 2002; Gehring). The activities and quality of life are reported to be easier to manage when individuals become more active, and feelings of self-worth are increased (Insel & Roth, 2004; Leiberman, 2002).

Individuals with cognitive disabilities appear to age at a faster rate than the general population and experience chronic health problems earlier (Fox & Rotatori, 1981, 1982; Gabler-Halle, Halle, & Chung, 1993; Seltzer & Meyer, 1965). The health and fitness needs of individuals with cognitive disabilities are the same, if not greater than the general population. Research suggested that health related physical fitness decreases as the level of cognitive disability and age increases (Gibson, 1997; Polednak and Auliffe, 1976; Wallstrom, 1993).

# Economics of Overweight and Obesity

The health and financial impact of excess weight on Americans is immense, effecting morbidity, mortality, and healthcare costs (Insel & Roth, 2004; USDHHS, 1996). The marked economic impact of obesity, overweight, and linked health problems on the U.S. Health care system is demonstrated in Table 1 (USDHHS, 2000, 2004). Direct and indirect medical costs are associated with the economics of overweight and obesity. Costs directly associated with obesity related medical care

### Table 1

Payment	Data So	ource
<u>Category</u>	<u>MIEPS</u>	<u>NHA</u>
Medicaid Medicare Private Out of pocket Total		\$14.1 23.5 28.1 <u>12.8</u> 78.5

Billions of Dollars, 1996 - 1998

Note: Adapted from Finkelstein, Fiebelkorn, and Wang, (2003) (CDC) table of Aggregate Medical Spending, in Billions of Dollars, Attributable to Overweight and Obesity, By Insurance Status and Data Source, 1996–1998

include preventive, diagnostic, and treatment services. The economics of obesity include morbidity (decreased productivity in the workplace from absenteeism, illness, and restricted activity) and mortality (premature death and loss of future income). The CDC (2004) estimated national medical costs attributed to overweight and obesity at between \$51.5 billion (Medical Expenditure Panel Survey [MIEPS]) and \$78.5 billion from 1998 data (\$92.6 billion in 2002 dollars) (National Health Accounts [NHA]), and accounted for 9.1% of total U.S. medical expenditures. Obesity 1998 costs alone were estimated at between \$26.8 billion (MIEPS) and \$47.5 billion (NHA).

The CDC developed obesity cost data for individual health insurance status and socio-demographic characteristics, concluding that Medicaid and Medicare paid approximately one-third to one-half of these costs (expenditures for residents of nursing homes or institutions were

not included). Healthcare costs for uninsured individuals were not addressed and likely include some individuals with disabilities and their families (Millan, 1993). It has been estimated that 26.6% ( $\pm$  1.4) of Oklahomans, Oklahoma county (23%  $\pm$  2.9), and the Oklahoma City metropolitan area (24.9%  $\pm$  2.4) (vs. 14.1% of the U.S. population) do not have medical coverage (BRFSS, 2004).

Allocation of public health resources and the economic impact of obesity at the state-level necessitated that estimates be made to assist state policymakers in predicting direct obesity-related Medicaid and Medicare expenditures (Table 2). Financial estimates were made through the Finkelstein, Fiebelkorn, and Wang project commissioned by the CDC (2004), using three years of data (1998-2000) from the Behavioral Risk Factor Surveillance System (BRFSS), 1998 MIEPS, and two years (1996 and 1997) of NHIS data. The estimated annual obesity-related medical expenditure for 6.0% of Oklahoma's population was \$854 billion.

Research studies are emerging that indicate a high risk of

#### Table 2

	Tota <u>Pop %</u>		on <u>\$</u>	Med <u>Pop %</u>		-	Medi <u>Pop %</u>		lion \$
Oklahoma	6.0	\$	85	7.0	\$	227	9.9	\$	163
Total U.S.	5.7	\$75	,051	6.8	\$1	7,701	10.6	\$2	1,329
Note: Figure attributable									ed Adult Obesity- 100)

ESTIMATED DIRECT MEDICAL COSTS ATTRIBUTED TO OBESITY

developing chronic health problems exists for persons with cognitive disabilities, and the health care available is inadequate (Frey & Rimmer, 1995; Horowitz et al., 2000; Rimmer, Braddock, & Marks, 1995). The U.S. government (U.S. Department of Health Education and Welfare [USDHEW], 1967, 1979; USDHHS, 1980, 1992, 1995, 1996; WHO, 1980, 1995, 1997, 1998) and Special Olympics (2001) have issued reports and called for assistance to remediate recognized health disparities faced by individuals with disabilities (Gregg, Hrycaiko, Mactavish, & Martin, 2004; Horowitz et al.; Pitetti, Jackson, Stubbs, Campbell, & Batter, 1989).

Researchers have pointed to poorly planned deinstitutionalization as the culprit for lower levels of health and insufficient healthcare among this population (Horowitz et al., 2000). Horowitz et al. also called for a national registry to track the healthcare of individuals in this population. It should be noted that inadequate attention to healthcare, associated illnesses, and physical disabilities was prominent in institutions (Smith, Decker, Herberg, & Rupke, 1969). Rotatori, Switzky, and Fox (1981) produced a community living skills assessment inventory to facilitate deinstitutionalization of the severely developmentally disabled that could be useful in identifying transition training areas important to health related matters.

## Cognitive Disability Overview

Pertinent studies were located in multiple, disconnected, discipline specific pockets reminiscent of the approach followed for many years by

the system that educates and supports individuals experiencing cognitive disabilities. These individuals may enter the system at a very early age. Individuals with visible disabilities, as with many syndromes, may be classified with moderate to profound cognitive disabilities and begin segregated specialized care soon after birth (American Psychiatric Association [APA], 2000). The move for early intervention to lessen the effects of and risk for educational failure were mandated in 1983 to begin at birth and continue until entry into the public education system at age 3 years. Positive effects of early intervention have been chronicled in research. While beneficial in some respects, it is possible that habitual segregation occurs in every aspect of the lives of individuals with cognitive disabilities. They learn to be segregated. Many of today's young adults with moderate cognitive disabilities (now 22 years old) were born before early intervention was mandated. While some individuals in that age range received early intervention and are reaping its benefits, they are likely to be the minority.

There has been a failure to weave the threads from research conducted within the many separate domains of life experienced by individuals with cognitive disabilities, into a blanket that covers their multiple needs. This may have affected their overall fitness and health. Mental retardation (MR), referred to as a cognitive disability throughout this paper, is a condition with onset of concurrent intellectual and adaptive behavior deficits during the developmental period (gestation

through age 18) (APA, 2000; Haak, 1989; Myers & Hammill, 1982; Reynolds & Fletcher-Janzen, 1989; Robinson & Robinson, 1976; Zeigler, 1993). A study commissioned by Special Olympics International stated that 170 million persons worldwide experience cognitive disabilities (Siperstein, Norins, Corbin, & Shriver, 2003). The requirements for MR diagnosis have fluctuated (Figure 1); currently it requires an IQ score at least two or more standard deviations below the mean (70 or less) on an age-standardized test (Emerson, Hatton, Bromley, & Caine, 1998;

### Figure 1

COMPARISON OF	MENTAL RETAR	DATION DEFINIT	TON SCHEMES	
AAMR 2002		AAMD	Educational	Psychiatric/
Support Levels		1973	1971	Legal 1971
	IQ 90 —		Borderline or	
	85		Slow Learner	
	80	Borderline		
	75	Retardation		
	70			
Intermittent	65	Mild	Educable MR	Moron
	60	Retardation	(EMR, EMH	
T · · · 1	55			
Limited	50	Moderate		_
	40	Moderate	Trainable MR	
Extensive			(TMR, TMH)	Imbecile
Lincollorve	30—	Severe	(11111, 1111)	miscone
	25			
	20——		Custodial or	
Pervasive		Profound	Dependent MR	
	10			Idiot
	5			
	0			

Note: Adapted from J. N. Drowatzky, 1971. Physical Education for the Mentally Retarded (p. 6). Philadelphia, PA: Lea & Febiger. Grossman, H. J. (1993). Classification in Mental Retardation. Washington, DC: American Association on Mental Deficiency. Abbreviations: AAMR = American Association on Mental Retardation; AAMD = American Association on Mental Disabilities; IQ = intelligence quotient; MR = mentally retarded; H=handicapped. Telzrow, 1989). Concurrent deficits must also be exhibited in adaptive behavior areas expressed as conceptual, social, or practical skills on an appropriate adaptive behavior scale (American Association on Mental Retardation [AAMR], 2002; APA).

In 1992, level of needed support was advocated as an additional criterion for defining MR (Luckasson et al., 1992). Prior to adopting the 1973 AAMD definition, 16% of all persons were classified with MR based on IQs up to 85 (Auxter & Pyfer, 1989; Grossman, 1983; Hardman, Drew, & Egan, 1987). Currently, the reported MR prevalence rate varies from 0.96% to 3% of the general population (Emerson, Hatton, Bromley, & Caine, 1998; Fujiura, 2003; MacMillian, Siperstein, Gresham, & Bocian, 1997; USDE, 2001). During the 1999-2000 school year, 614,433 U.S. students, aged 6 through 21, received special education services (Turnbull et al., 2004). During the 1991-1992 school year, 10.02% of enrolled students received special education services, with 1.14% classified with MR, 5.02% with learning disabilities, 2.34% with speech impairments, 0.89% with emotional disturbances, and 0.63% with other disabilities (USDE, 1993; Ayers, 1994). Demographics for secondary school students (1985-1986 school year) revealed that 68.5% of persons served by special education were male (compared to 49.8% of the general population), and 33.6% lived in suburbs (compared to 47.9% of the general school population).

MR has been classified by cause (etiology) and degree of severity

(Hallahan & Kauffman, 1978). The etiology of MR has evolved over time (Table 3) and is dependent on orientation (medical, behavioral, or educational) and sometimes interaction (AAMR, 2002; Turnbull et al., 2004). Etiological classification has limited value due to individual human differences and environment. For reference, it has been estimated that 60% to 89% of individuals with cognitive disabilities are labeled as mild (IQ of 50 to 70); 7% to 32% are labeled as moderate (IQ of 35 to 55); and 4% to 8% of individuals are labeled as severe (IQ of 25 to 40) or profound (IQ below 25) (Baroff, 1991; Grossman, 1983; Patton, Payne, & Beirne-Smith, 1990; Siperstein et al., 2003). Even after diagnostic evaluation, the percentage of individuals with cognitive disabilities of unknown origin varies from between 30% to 50% up to 78% (Curry et al., 1997; Patton, Payne, & Beirne-Smith, 1990; Schaefer,

Table 3

EVOLUTION OF COGNITIVE DISABL	LITY (MR) ETIOLOGY
EXOGENOUS	ENDOGENOUS
Brain damage, injury	Heredity or environment
ORGANIC/BRAIN-DAMAGED	CULTURAL-FAMILIAL
Accident or injury before, during, or after birth	Social factors (poor environment), or genetic (inherited)
TIMING	TYPE
Prenatal, perinatal, postnatal	Behavioral, biomedical, educational
Note: Adapted from Hallahan, D. P., & K Special Education.	Xauffman, J. M. (1978). Exceptional Children: Introduction to

& Bodensteiner, 1992; Yeargin-Allsopp, Murphy, Cordero, Decoufle, & Hollowell, 1997).

Much of the widely used negative, stereotypical terminology (such as moron, feebleminded, idiot, retarded, and imbecile) used to classify individuals with cognitive disabilities is offensive. Kanner's (1948) use of descriptive terms to classify mental deficiency into three groups, proved accurately objective: (a) absolute [markedly deficient needing custodial care]; (b) relative [inability to fully meet society's expectations, yet able to work]; and (c) apparent or pseudo [learning, emotional, health, or physical problems]. The AAMD classification of MR by psychiatrists and psychologists was standardized to the bell curve from a continuum of degrees of severity determined by IQ scores on age-normed tests by standard deviations from average (normal) intelligence.

Reference terminology has been revised to descriptively reflect diminished intellectual and social functioning with universal application to traits (mild, moderate, severe, and profound retardation) and educational capacity (educable, trainable, and custodial) (Cartledge & Milburn, 1978; Hallahan & Kauffman, 1978). The range of IQ scores used to classify children with MR have varied between the AAMD (68 or 69) and educators, who often used a higher IQ (75) cutoff score (see Figure 2) (Hallahan & Kauffman).

The American educators' unsanctioned system that continues to survive was considered descriptive of MR programming needs: (a)

Figure 2

Classification System				Intellige	ence Quotie	ent
100 95 90 85 80 7	5 7	0 65 60	55	50 45 4	0 35 30 2	5 20 15 10 5 0
American Association on Mental Deficiency		Mild	M	oderate	Severe	Profound
American Educators	E	ducable	·	Tra	unable	Custodial
Mental Deficiency Groups (1948)		pparent		-	lative	Absolute
Note: Adapted from Hallahan, D. P., & Ka Special Education, pp. 68. Englewood Clij						

COMPARISON OF CLASSIFICATION BY SEVERITY OF COGNITIVE DISABILITY

educable (some basic academics); (b) trainable (functional life skills, selfhelp, and vocational); and (c) custodial (totally specialized care, institutional) (Hallahan & Kauffman, 1978; Weicker, 1987). Problems with this system include blanket literal application of these terms and heavy dependence on IQs to determine educational objectives, which has denied access to academic subject matter and social situations within intellectual and behavioral reach of many children labeled as trainable or severely mentally retarded.

When considering community programs (such as exercise or sports activities) for individuals with cognitive disabilities, recognition of a tendency to have transportation problems, significant delays in motor skill development, and physical limitations has to occur (Bender & Valletutti, 1985; Calculator & Jorgensen, 1994; Campbell, 2000; Downing, 1996; Kavale & Mattison, 1982; Krebs & Block, 1992; Lakin,

Hill, & Bruininks, 1998; Stone, 1977). In addition to adaptive behavior deficits, typically an individual with cognitive disabilities has difficulties with motivation, incidental learning, memory, and generalization of information, which might predispose movement to different contexts (Drabman, Hammer, & Rosenbaum, 1979; Turnbull et al., 2004).
Adaptive behaviors, conceptual perceptions, social, and practical skills of these individuals may vary according to environment, experiences, age, and cultural expectations (Schalock, 1999; United Nations Education, Scientific, and Cultural Organization [UNESCO], 1989, 1991).

Table 4 provides a combined view of support levels, educational classifications, and 1993 AAMR defined categories that lend insight into individual functioning in typical environments experienced in daily community life (Grossman, 1993; Luckasson et al., 1992). Intelligence testing and adaptive behavioral assessment can be controversial, inappropriate, and fraught with inaccuracies and problems (such as normed sample, cultural or examiner bias, and lack of prior exposure to material) (Brown & Snell, 2000; Popham, 1999; Witt, Elliott, Kramer, & Gresham, 1994). Many individuals classified with mild MR in school may function quite adequately and normally elsewhere (President's Committee on Mental Retardation, 1970; President's Council on Mental Retardation, 1999). Individuals with moderate disabilities often have significant communication difficulties that place barriers on them in society.

### Table 4

Level of Support	AAMR and Education Classifications	Description of Needed Support	Impact on Health-Related Fitness and Instruction
Intermittent	Mild MR Educable IQ (50-55 to 70)	As needed; episodic; short-term; high or low intensity	Transportation; Method of instruction (ability to 6th grade). Few early motor delays. Problems with socialization and need for structure. Identified in school.
Limited	Moderate MR Trainable IQ (35-40 to 50- 55)	Support intensity consistent over time, short-term with less cost & people needed than for more intense support (e.g. training for employment)	Lack of exposure, may not understand rationale. Masked intelligence due to concomitant disability (e.g. communication, physical, vision, hearing, balance). Ability to 2nd grade for semi-skilled independent living and work. Motivation poor due to past failures. Short attention, hyperactivity. Clumsiness. Health problems.
Extensive	Severe MR Severely/multiply handicapped IQ (20-25 to 35- 40)	Long-term; consistent; regular involvement for some needs (e.g. home living)	Limited endurance and strength. Severe speech delays augmentation may be needed. Sensorimotor problems: muscle tone- tension. Significant intellectual & motor delays (may learn only basic rudimentary tasks with supervision).
Pervasive	Profound MR Severely/multiply disabled, IQ below 20 –25	Constant; consistent; high intensity; across environments; life altering; intrusive; more people & cost	Extensive neurological impairment often limits motor control and cognitive development. Difficulty sitting, moving, stiffness, health; limited self-care. Need basic therapeutic intervention Need equipment and aid. Physical therapy. May not achieve any self-care.

PROJECTED OUTCOMES AND NEEDED SUPPORTS BY MR CATEGORIES

*Note:* Successive levels include preceding categories. Adapted from H. J. Grossman (1977) and Cottrell (1985).

### Attitudinal Barriers

Special Olympics International commissioned Siperstein et al. (2003) to explore attitudes of the general population toward individuals with cognitive disabilities (referred to as intellectual disabilities). Faceto-face or telephone interviews were conducted during the spring and summer of 2003 from nationwide pools or selected cities. The sample included 7,200 randomly selected participants from 10 countries (800 from each country, 400 from each Ireland pooled) that included Brazil, China, Egypt, Germany, Japan, Nigeria, Northern Ireland, Republic of Ireland, United Kingdom, and United States. A convenience sample of 200 persons from Special Olympics events in the U.S. and Japan were included in the above figures. The research design was piloted prior to implementation of the study.

Although the current philosophy is acceptance of individuals with cognitive disabilities and inclusion in the mainstream of life; research demonstrated that these persons are not accepted by the general public (Siperstein et al.). Major acceptance barriers voiced by the U.S. sample were: lack of school resources and teacher preparedness (78%); lack of job training (76%); lack of community services (67%); negative attitudes (by neighbors [53%], fellow employees [61%], and students [66%]). The degree to which individuals with intellectual disabilities can live, work, learn, and recreate in the community is partially determined by public attitudes and society's expectations. Stigmatizing perceptions of the U.S.

sample that might affect quality of life for persons with cognitive disabilities were: (a) 54% of interviewees thought they were incapable of activities more complex [such as understanding the news] than feeding or dressing themselves; (b) 53% thought learning was impeded, discipline problems increased, and a danger was posed to others when students with disabilities were included in regular classes; (c) 82% thought they could not handle an emergency; (d) 75% thought these individuals should live supervised lives in family homes [49%], group homes [17%], and institutions [9%]; and (e) 79% thought their education should occur in segregated settings away from regular students [such as at home or special schools].

When U.S. respondents shared their opinions about sports and leisure activities for individuals with intellectual disabilities, the majority (64%) thought they were only capable of participating in team sports with their peers having disabilities. Only 11% of respondents thought integrated team participation was possible of persons with cognitive disabilities. When interviewed about the important issue of health care, the majority of respondents (53%) thought it was equivalent for persons with and without disabilities; some thought it was worse (27%), and others (20%) thought health care for persons with disabilities was better. Although a percentage was not provided, U.S. interview respondents thought individuals with cognitive disabilities were capable of selfdetermination (Siperstein et al., 2003). When compared to follow-up

studies of individuals with cognitive disabilities, the findings reflected were consistent.

### Prevalence of Overweight and Obesity

The majority of obesity and overweight prevalence investigations on persons with cognitive disabilities began in the early 1970s, coinciding with the late 1960s deinstitutionalization movement that resulted in less restricted lives and a dramatic residential shift from institutions to community-based settings (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990). The purpose for conducing many early obesity prevalence studies appeared to be understanding characteristics, physical capacities, limitations, and medical needs of this population.

Investigations exploring the prevalence of overweight and obesity in the population of individuals with cognitive disabilities, were included in this review of literature to provide historic detail of criterion used to define and establish incidence. Table 5 provides a brief chronological overview of prevalence studies included in the more in-depth narrative review of literature. The measurement techniques employed in conjunction with defining overweight and obesity criterion are briefly described. Topics that emerged from the prevalence studies reviewed included possibility of weight variance by genotype, level of cognitive disability, gender, living arrangement, and other pertinent factors; comparisons were made to persons without disabilities in the general population. Health-related studies focused on cardiovascular endurance

Year & Study	N, Sex	Age & Levels	Setting	Measures	Criterion & Results
1970 - Nordgren	63 M=39, F=24	Age: 19-39 IQs 30-70	Sweden: Sheltered workshops	Weight & height; 3 Skinfolds (right upper arm, abdomen, subscapular)	No criterion reported; Greater SF thickness in men with MR; No significant difference between women with & with-out MR
1974 - Kreze, Zelina, Juhas, & Garbara	554 (8 MR) M=334, F=220	Age: M 18-58, F 18-50 8 Mild (lQ ≤70)	Czechoslovakia: Various worksites	Standardized table of weights for height	<ul> <li>20% overweight = obese</li> <li>Obesity prevalence: 41.9%</li> <li>when IQ &lt; 90; 21% when IQ</li> <li>91-110; 10.7% when IQ &gt;1111;</li> <li>Level MR &amp; obesity inversed</li> <li>in females</li> </ul>
1976 - Polednak & Auliffe	161 M=108, F=53	Age: 18-73 51 Mild 62 Moderate 34 Severe	Canada: Institution	Weight & height; Skinfold (triceps); Circumference (upper arm)	% overweight = obese: M ≥ 20%, F > 30% overweight Results: M = 20.4%, F=17.0% obese; IQ & gender not linked
1980 - Wallen & Roszkowski	149 M=92, F=57	Age: 18-55 Mild to Profound	United States: Institution	Standardized table of weights for height	> 10% above ideal wt = obese ResultsObese: M 26%, W 44% obesity greater in mild/mod obesity greater with age
1982 - Fox & Rotatori	1,152 M=646, F=506	Age: 18-75 Mild to Profound	United States: 4 settings 2 institutions (public & private); 2 community	Standardized table of weights for height	<ul> <li>20% above desirable = obese</li> <li>Obese: M 15.5%%, F 25.1%</li> <li>Higher in Mild/Moderate</li> </ul>

PREVALENCE OF OBESITY IN PERSONS WITH COGNITIVE DISABILITIES

Table 5

			based (workshop & semi- residendial facility)		(66.2%) (M 27.9%, F 38.3%); Severe/Profound (20.9%) (M 6.9%, W 13.6%)
1985 - Fox, Hartney, Rotatori, Kurpiers	337 М & F	Age: 5.5 - 15.4 <sub>5</sub> United States; MR	United States:	Standardized table of weights for height	Based on Ht & Wt index: 22% were obese; More children with MR obese than without; Obesity not linked to IQ, gender, age, rac
1986 - Kelly, Rimmer & Ness	553 M=343, F≈210	Age: 18-40 52 Mild 138 Moderate 142 Severe 219 Profound	United States: Institution (Texas)	Combined skinfolds & girth; GRE to find % body fat & density	Over weight Level: M > 20%, W > 30% Obese: M 45.2%, F 50.5% (higher across all levels of MR; higher prevalence in mild to Moderate
1988 - Cronk, Crocker, 730 Pueschel, Shea, Jachai M & Pickens, & Reid	, 730 I M & F	Children with Downs (6,450 observations)	United States: Community & Institutions	Studied stature & weight; Developed growth charts (5 centiles) for 2 age groups for persons with Downs	<ol> <li>Charts sensitive to sample size &amp; not validated; (2) Taller &amp; heavier if living in community;</li> <li>Overweight from late infancy;</li> <li>Link - short stature &amp; lower legs; (5) Link - activity problems</li> <li>&amp; lower legs; (6) Growth linked to living arrangement &amp; activity opportunities</li> </ol>
1991 - Simila & Niskanen	112 M=52, ₽=60	Age: all 20 yr 43 Mild 34 Moderate 21 Severe 14 Profound	Finland: Locations (2): institutions & clinics (child welfare, public health)	Weight & height, 3 BMI categories (< 20% under wt, 20 - 24% normal, >25% over wt)	Obesity = BMI > 30 kg/m <sup>2</sup> M 13.5%, F 20.0% More obese & extremely obese than in general population; BMI lower in Profound than in Mild levels

BMI <u>&gt;</u> 30 kg/m² Obese: M 19.04%, F 34.61%	Over Wt: M ≥ 20%, W > 30% Obesity in persons/Downs: M=42%, F=61% Finding: %BF for persons with & without Downs was the same within gender Mean %BF: M 21.0%, F 31.0%	Body fat: M >25%, F >30% Obese: M 27.5%, F 58.5% Findings (p< 0.001): (1) Obesity more prevalent females than males; (2) Obesity more prevalent in Mi-Mod than Severe; (3) Obesity more prevalent in less restrictive settings (obesity less in institution)	Obesity Prevalence: Without disabilities: M=19%, F=28% With MR M=27.5%, F=58.5%	Institutionalized: lower BMI, BF%, triglyceridees, ratio of total cholstereol to high-
Weight & height, BMI	Compared BF% in persons with MR, with & without Downs	GRE using skinfolds to find BF%	Compare obesity prevalence in persons with & without disability	Weight, height for BMI; blood tests
England: Community: hostel, flatlet (supervised), family home	United States	United States: Locations (4): Institution, ICFMR, Group home, family home	United States: National Center for Health Statistics (1973)	United States: institutions, group home, family home
Age: 20-68 Mild to Profound	Age: 17-72 MR with (31) & without (294) Down's	Age: 17-72 (Mean 36.8 yr) Mild to Profound	364 MR U.S. national vs. comparison 28,043 of prevalence ND MR and ND	Aged: 17-70 Compare health pattern
183 M=105, F=78	325 M=183 F=142	364 M=204, F=160	364 MR vs. 28,043 ND	329
1992 - Bell & Bhate	1992 - Rimmer, Braddock, & Fujiura	1993 - Rimmer, Braddock, & Fujiura	1993 - Rimmer, Braddock, & Fujiura (part 2 of study)	1995 - Rimmer, Braddock, & Marks

density lipoproteins; higer intake of medications. Group home: smoked & drank more, exercised least. Family home: more obese.	Females more obese (higher %BF, BMI, & weight) Persons in family homes more obese (higher %BF, BMI, & weight) than in institutions. Persons in U.S. more obese (higher %BF, BMI, & weight) than in Germany	Criterion: 30 kg/m <sup>2</sup> Obesity more prevalent in MR High levels of cholesterol & meds in MR; Little structured execise in MR; Significant variables = age, gender, level MR, clinical syndrome, & drug therapy	Criterion: BMI ( $F \ge 27.3$ and M $\ge 27.8$ ); Persons with Downs more often overweight; More overweight in family homes; Major chronic health risks
	Weight, height for BMI; Skinfold for %BF	Weight, height for BMI	Weight, height for BMI
	Germany and U.S.: Compared prevalence of obesity in family homes & institutions	United States: Reviewed medical & habiliation files for persons in 7 counties	United States: Compared prevalence of overweight in persons with Downs in family & group homes; & to Healthy People 2000 criteria
Mild to Profound	Aged: 18-59 Mild to Profound	Aged: 18-83 (mean 37 yrs) MR, receiving habilitation services	Aged: 15-69
	1995 - Frey & Rimmer 210	п 1,021 M=574 F=447	oine, 283 McGuire
	1995 - Frey &	1997 - Gibson	1998 - Rubin, Rimmer, Chicoine, Braddock, & McGuire

2003 - Harris, Fada, Rosenberg, Jangda, O'Brien, & Gallager	1,749 M=1,102 F=647	Aged: 9 & over Sp Olympic World Games 1999 & 2000 Mild-Profound	United States: Screening of Sp Olympic athletes to determine worldwide incidence of obesity (n=562 U.S., n=1,187 outside U.S.)	Weight, height for BMI	Criterion: 25 kg/m <sup>2</sup> U.S. athletes: more likely to be overweight or obese (3.1 to 4.9 times); Below age 18 yrs close to 1/2 obese; 18+ yrs over 1/2 obese (trend similar to general U.S. population). No BMI standards established for persons with disabilities.
2003 - Marshall, McConkey, & Moore	464 (IQs 80- 20)	Aged: 10+ yrs (Followed 122 overweight) (20 in educ program)	Northern Ireland: Screened by Health and Social Services Trust; 2 part study: 1) follow-up of obese/overweight and 2) results of nurse directed health & weight loss 6-8wk education program )	Weight, height for BMI; Surveys; Follow-up at 3 mo; Nurse directed health & weight reduction program	Criterion: BMI and weight High blood pressure in 40-49 age group. Identified as over- weight or obese: 64% 20+ yrs; 26% 10-19 yrs.; On 3-mo follow survey 34% tried weight loss (3 successful). Concluded: Screening alone insufficient to prompt action. Nurses' program produced weight & BMI reduction.
2004 - Braunschweig, Gomez, Sheean, Tomey, Rimmer, & Heller	48 MR	Adults; Lived in community; Cardiovascular health study	United States: Health-related fitness cardiovascular endurance study provided incidence information supportive of previous studies	Weight, height, blood tests, waist circumference, & food consumption frequency	Criterion: BMI <u>&gt;</u> 27.5 89% overweight or obese; 54% with large waists (abdominal fat deposits indicating possible cardiovascular problems
Notes: GRE = generalized regressio retardation; ND = no disability; SF	l regressior ubility; SF =	n equation; RE = reg = skinfold	Notes: GRE = generalized regression equation; RE = regression equation; %BF = percent body fat; BMI = body mass index; MR = mental retardation; ND = no disability; SF = skinfold	body fat; BMI = body m	ass index; MR = mental

have included descriptive demographic BMI data that tends to support prevalence findings (Braunschweig, 2004; Croce & Horvat, 1992; Neggers, Stitt, & Roseman, 1989).

### Review of Prevalence Studies

# Nordgren (1970, 1971)

Nordgren conducted a workplace study in Sweden to determine the physical capabilities of 63 participants (39 males, 24 females) with cognitive disabilities (IQs ranged from 30 to 70) that worked full time in sheltered workshops. The participants ranged in ages between 19 and 39 years. Anthropometric measurements performed on participants (height, weight, and 3-skinfolds [upper arm, abdomen, & subscapular]) were used to estimate body fat percentage and make comparisons to an unspecified population without disabilities. Nordgren and Backstrom (1971) explored possible correlations between strength and work performance in these participants with cognitive disabilities, but did not report any direct comparisons with the muscle mass component of body composition.

Nordgren (1970, 1971) reported that males with disabilities had significantly greater skinfold thicknesses at each site than men without disabilities (a possible a reflection of increased muscle from manual work rather than fat). He found no statistically significant difference in skinfold thicknesses in females with and without disabilities. The later conclusion conflicts with most published U.S. studies, which have found

obesity problems to be greater in individuals with cognitive disabilities (such as Fox & Rotatori, 1982; Kelly, Rimmer, & Ness, 1986; Rimmer, Braddock, & Fujiura, 1993; Similia & Niskanen, 1991; Wallen & Roszkowski, 1980).

## Kreze, Zelina, Juhas, and Garbara (1974)

Researchers studied the occurrence of obesity in various worksites in Czechoslovakia among 554 participants (334 males, 220 females), 18 to 58 years of age, with differing occupations and levels of education. The sample was divided into three IQ levels (low, average, and above average). A standardized chart was used to analyze participant weight levels (obesity was defined as weight 20% or more above ideal) derived from height and weight measurements. Kreze et al. (1974) reported an inverse relationship existed between IQ and prevalence of obesity (higher prevalence of obesity at lower IQs) that was stronger in females than males. Kreze et al. reported that 41.4% of females in the lower IQ group (IQ < 90) were obese while only 10.7% in the above average IQ group (IQ > 111) were obese. The findings of Kreze et al. (1974) and Nordgren (1970, 1971) were in agreement, but conflicted with more recent research (Fox & Rotatori, 1982; Kelly, Rimmer, & Ness, 1986; Rimmer, Braddock, & Fujiura, 1993). The Kreze et al. investigation is often cited as an obesity prevalence study for persons with cognitive disabilities, however, the generalizability of the researchers' findings are limited because only 8 (1.4%) of the 554 study participants had IQs of 70 or less.

## Polednak and Auliffe (1976)

The researchers studied 161 persons (108 males, 53 females; aged 18 to 73) in Canadian institutions with varying levels of cognitive disability (51 mild, 62 moderate, 48 severe). Participants were described as having Down syndrome (13), tuberous sclerosis (1), phenylketonuria (PKU) (1), epilepsy (75), and only as obese (20).

The criterion for obesity was set at 20% over ideal weight for males and 30% over ideal weight for females. The researchers defined obesity from skinfolds as one standard deviation greater than the general population mean (Seltzer & Meyer, 1965). Anthropometric measures performed in this study were height, weight, triceps skinfold, and upper arm circumference. Differences in mean body measurements by MR level and gender were not statistically significant, although slightly higher at the moderate level. Obesity was found to be more prevalent in men (20.4%) than women (17.0%), in agreement with older studies (Kreze et al., 1974; Nordgren, 1970, 1971), and in conflict with more recent findings (Fox & Rotatori, 1982; Kelly, Rimmer, & Ness, 1986; Rimmer, Braddock, & Fujiura, 1993).

The possibility of age related obesity was noted with caution in the Polednak and Auliffe (1976) study. When the sample was considered as older or younger than age 40, the frequency of obesity was higher in males than females in the younger group with the inverse occurring in the over 40 group.

## Wallen and Roszkowski (1980)

This study occurred in an U.S. and institution included 149 participants (92 males, 57 females; aged 18 to 55) diagnosed with mild to profound cognitive disabilities. Individuals diagnosed with Down syndrome (8) and epilepsy (45) were included in the study. Height and weight measurements were performed and compared to the Metropolitan Life Insurance Desirable Weight Table (1959) that were based on age, gender, and physician's estimate of body frame (USDHEW, 19670). The criterion for overweight was set at 10% above ideal tabled weight. More females (44%) than males (26%) were determined to be obese across all levels of retardation. Researchers stated that males were more often underweight than overweight.

## Fox and Rotatori (1982)

The study included 1,152 persons (646 males, 506 females; aged 18 to 75) with mild to profound cognitive disabilities. The participants came from four U.S. settings (public and private institutions, a sheltered workshop, and a semi-residential facility). Anthropometric height and weight measurements were performed with obesity criterion set at 20% or more above desirable weight. Researchers found the prevalence of obesity in individuals with cognitive disabilities to be: (a) higher in females [25.1%] than males [15.6%]; and (b) higher in persons with mild to moderate (27.9% male and 38.3% female) than severe to profound impairments (6.9% male and 13.6% female). A statistically significant

relationship was found between age group and weight status, with level of obesity increasing with age.

## Fox, Hartney, Rotatori, Kurpiers (1985)

Their research investigated the prevalence of obesity in 337 children and adolescents (age range 5.5 to 15.4 years) diagnosed with cognitive disabilities. The obesity criterion was based on a weight-forheight index, with 22% of participants fitting this category. Researchers concluded that obesity was more prevalent in children with cognitive disabilities than without. Researchers found no significance in the prevalence of obesity related to age or race. Their findings that no significant differences existed in the prevalence of obesity by sex or level of cognitive ability for this sample of children and adolescents conflicted with findings of their peers.

## Kelly, Rimmer, and Ness (1986)

The prevalence study included 553 (343 males, 210 females) ambulatory persons from a Texas state run institution. Participants ranged in age from 18 to 40 years (male mean age = 27.97 years and females = 27.07). The four levels of cognitive impairment were represented in the sample: (a) mild [34 males, 19 females]; (b) moderate [97 males, 42 females]; (c) severe [96 males, 46 females]; and (d) profound [116 males, 103 females]. Participants' body fat percentage and body density were predicted using generalized regression equations derived from skinfold and girth measurements. Different formulas were

used for males (Jackson & Pollock, 1978) and females (Jackson, Pollock, & Ward, 1980). Obesity was defined as body fat percentage > 20% for males and > 30% for females.

Statistically significant main effects were revealed in comparisons of body fat by gender and level of cognitive disability. The prevalence of obesity was higher in: (a) females [50.5%] than males [45.2%] across levels of cognitive disability; and (b) obesity became more frequent in both genders as the level of retardation decreased from profound to mild. A post hoc analysis revealed that participants with profound cognitive disabilities had significantly lower percentages of body fat than persons with mild and severe levels of retardation. Researchers rationalized that the finding could be linked to the greater availability of disposable income (to purchase food and snacks) for participants with mild to moderate cognitive disabilities that were more able to work. *Cronk, Crocker, Pueschel, Shea, Zackai, Pickens, and Reed (1988)* 

Researchers studied the weight and stature of 730 children with Down syndrome (4,650 observations) because these persons are characteristically short in stature, have weight problems, and have been linked with chronic illnesses. Study findings reported: (a) children with Down syndrome raised at home were taller and weighed more throughout the growth period than those from subsamples in institutions; (b) growth spurts experienced by adolescents with Down syndrome were less vigorous than in individuals without disabilities; (c) sitting height

measurements for adolescents with Down syndrome revealed shorter stature was possibly due to short legs; (d) with height being similar, it was suggested that environment [living arrangements], emotional support, and opportunities for activities might play a role in growth during childhood and adolescence; (e) weight gain was more rapid than growth in height for children with Down syndrome throughout the growth period, especially during infancy and adolescence; (f) many children with Down syndrome are overweight by the time they are 36 months of age; (g) the tendency for children with Down syndrome to be overweight was noted from late infancy throughout their growth period; (h) on average, children with Down syndrome experiencing moderate to severe congenital heart problems were shorter and lighter than those with mild heart problems [males were 2 cm shorter and 1 to 2 kg lighter, and females were 1 cm shorter and 1 kg lighter]; and (i) individuals with cognitive disabilities that experienced lower extremity problems had more difficulty participating in physical activities than others without these difficulties.

Growth charts (length and head circumference) are useful for providing early warning of potential problems (such as obesity, poor lactation, failure to thrive, and progressing hydrocephalus) until approximately age 24 months, and make monitoring possible (Valman, 1980). When growth charts and tables are normed on the general population, the ideal weights for height produced may not be appropriate

for many children and adults with disabilities. Few standardized growth charts have been developed and validated for children with various syndromes.

Cronk et al. (1988) developed two sets of growth charts with five centiles, for children with Down syndrome that were gender and age specific (1 to 36 months, and 2 to 18 years); with individuals that experienced congenital heart problems included in the norm group. The growth charts were to be used in conjunction with NCHS produced charts. The researchers conceded that the growth charts developed were sensitive to sample size. Validation of Cronk et al. (1988) growth charts or others for individuals with Down syndrome was not located in the literature. Cronk et al.'s stated findings were supportive of previous researchers (Benda, 1939; Centerwall & Centerwall, 1966; Cronk, 1978; Kugel & Mohr, 1963; Pueschel, Rothman, & Ogilby, 1976; Rarick & McKee, 1949; Rarick & Seefeldt, 1974; Roche, 1965, 1967; Smith & McKeown, 1955; Thelander & Prior, 1966).

# Simila and Niskanen (1991)

The incidence of over and under weight was investigated in 112 young adults at age 20 years (52 males, 60 females), with cognitive disabilities (43 mild, 34 moderate, 21 severe, 14 profound). The study was conducted in institutions, child welfare clinics, and public health centers in Finland. Participant weight and height measurements obtained were used to calculate BMI estimates that were divided into five

categories: (a) < 20 kg/m<sup>2</sup> = underweight; (b) 20% to 24% = normal weight; (c) > 25% = overweight; (d) > 30% to 31% = moderate obesity; and (e) > 32% = severely obese.

The researchers concluded the prevalence of obesity: (a) was greater in females (20.0%) than in males (13.5%); (b) that obesity occurred more frequently in the study sample (33.2%) than the general population; and (c) that BMIs were higher in persons with mild cognitive disabilities than profound, which supported some previous research (Fox & Rotatori, 1982; Kelly, Rimmer, & Ness, 1986) and conflicted with others (Polednak & Auliffe, 1976).

### Bell and Bhate (1992)

This study was conducted in England to determine the prevalence of overweight and obesity in individuals with cognitive disabilities, including persons with Down syndrome (31.69%), living in the community (family home, hostel, and supervised flatlets). Participants included 183 persons (105 males, 78 females; aged 20 to 68 years) diagnosed with mild to profound cognitive disabilities. Height and weight measurements obtained were used to calculate BMIs, with the criterion for obesity set at BMI  $\geq$  30 kg/m<sup>2</sup>. Researchers determined that: (a) more females [34.61%] than males [19.04%] were obese; (b) obesity was more prevalent in persons with cognitive disabilities than without [males 19.05% vs. 6%; females 34.61% vs. 8%]; and (c) individuals with Down syndrome were obese more frequently than persons with cognitive

disabilities but without Down syndrome [males 70.58% vs. 49.29%; females 95.83% vs. 62.96%].

### Rimmer, Braddock, and Fujiura (1992)

The study compared blood lipid levels and body fat percentages found in 325 individuals aged between 17 and 72 years, with cognitive disabilities. The sample included 294 persons (162 males and 132 females) without Down syndrome, and 31 (21 males and 10 females) with Down syndrome. Obesity was defined as percentage of body fat > 20%in men and > 30% in women (McArdle, Katch, & Katch, 1991). These researchers concluded that: (a) body fat percentages were higher in females [mean 31.0%] than males [mean 21.0%]; (b) body fat percentages were not affected by Down syndrome; (c) obesity classification occurred in both groups of persons with cognitive disabilities at about the same rate; and (d) the presence of abnormally high lipid levels in lipoproteins indicated that males in this sample had a higher risk of developing coronary heart disease (CVD) than women. Researchers stated that persons with Down syndrome often appear more obese than other individuals due to their short stature.

### Rimmer, Braddock, and Fujiura (1993)

The purpose of study was to determine the effect of four residential living arrangements (most to least restrictive: institution, intermediate care facility [ICFMR], group home, and family home) on obesity levels in 364 (204 males, 160 females) adults (mean age 35.8 years <u>+</u> 11.2; range

17 to 72 years) with cognitive disabilities. Percentages of body fat were predicted for participants using skinfold measurement in different generalized regression equations, for males (Durnin & Womersley, 1974) and females (Jackson, Pollock, & Ward, 1980); obesity levels were set (males > 25% and females > 30%) (Buskirk, 1987; Jackson & Pollock, 2004; Powers & Howley, 1990).

Researchers concluded that living arrangement plays a significant role in the prevalence of obesity in persons with cognitive disabilities. The prevalence of obesity was significantly higher in females [58.5%] than males [27.5%] across all residential settings. The prevalence of obesity in persons with mild to moderate levels of retardation across settings was significantly higher than for persons with severe cognitive disabilities. Individuals living in institutions were classified as obese less frequently, and displayed significantly lower body fat percentages than persons living in less restrictive settings (ICFMR, group, and family homes).

When Rimmer, Braddock, and Fujiura (1993) compared their findings with study results from the 1973 NCHS (which is one of the largest U.S. databases that determines obesity) with 28,043 general population participants, the prevalence of obesity in individuals with cognitive disabilities (86%) was significantly greater than in persons without disabilities (47%). This obesity variance held for both genders (males 27.5% vs. 19% and females 58.5% vs. 28%).

## Rimmer, Braddock, and Marks (1995)

This study investigated the health characteristics and behaviors of 329 adults (aged 17-70 years) with cognitive disabilities living in three settings (institution, group home and family home). Participants' height and weight measurements were obtained to calculate BMI. Various blood tests and information on health behaviors (such as exercise patterns and use of alcohol, cigarettes, and medications) were included.

Individuals from the sample residing in institutions were more medicated than persons living in group or natural family homes. Persons living in institutions also weighed less, had lower BMIs with lower estimates of percentage body fat, lower triglycerides, and lower ratios of total cholesterol to high-density lipoprotein cholesterol than individuals that lived in less restrictive settings. Individuals residing in community group homes exercised less often than individuals living in family homes and institutions. Although the overall use of cigarettes and intake of alcoholic beverages was low for the sample, it was higher among individuals living in group homes. Individuals living in family homes had fewer external controls and were more frequently obese (higher BMI, body weight, and related blood levels) than individuals residing in institutions and group homes.

# Frey and Rimmer (1995)

This study compared the prevalence of obesity in 210 individuals (aged 18-59 years) living in institutions and family settings in Germany

and the United States. Height and weight measurements performed were used to calculate BMIs. Skinfold thickness measurements were used to estimate percentages of body fat. Study results indicated that: (a) percentages of body fat were higher in females than males; (b) percentages of body fat and BMIs were higher in individuals residing in family homes than in institutions; and (c) prevalence of obesity, percentages of body fat and BMIs were higher among individuals living in the U.S. than Germany. Researchers suggested that the variances in body fat percentages and BMI might be partially attributable to differences in American and German lifestyles (such as greater access to fast food and lower gasoline prices in the United States which might result in more frequent travel by car than walking or riding bikes). *Gibson (1997)* 

Data sources for this study were medical and habilitation service records of 1,021 adults (mean age of 37, range 18 to 83 years) from seven counties having a primary MR diagnosis. The prevalence of obesity in study participants (574 males [56%] and 447 females [44%]) was compared to samples drawn from general state and U.S. national populations. Height and weight measurements were used to estimate BMIs, with obesity defined as  $\geq$  30 kg/m<sup>2</sup>. The researcher used multivariate logistic regression with ratio estimates of obesity in the population studied to construct an appropriate model of combined variables to predict obesity.

The sample of persons with cognitive disabilities demonstrated a higher prevalence of obesity (19.2%) than estimates from state and national population samples. Significant factors that Gibson (1997) identified as influencing obesity included age, gender, severity of cognitive disability, drug therapy, presence of clinical syndrome, and presence of health complications (such as high levels of cholesterol). Gibson noted individuals in the study sample took part in little structured exercise.

# Rubin, Rimmer, Chicoine, Braddock, and McGuire (1998)

This study compared the living arrangements (family and group homes) and prevalence of obesity in 283 individuals with Down syndrome (age range 15 to 69 years) with *Healthy People 2000* (USDHHS 1991, 1992, 1995) BMI overweight criterion (males  $\geq$  27.8 and females  $\geq$ 27.3). Prevalence of overweight was higher in persons with Down syndrome than the general population. Individuals with Down syndrome living in family homes were overweight more frequently than persons living in group homes. Researchers concluded that individuals with Down syndrome are at risk for developing major chronic health problems.

## Harris, Fada, Rosenberg, Jangda, O'Brien, and Gallager (2003)

The prevalence of overweight among Special Olympic athletes was studied from a worldwide sample of 1,749 persons (63% male, 37% female) with cognitive disabilities taking part in 1999 and 2001 Special

Olympic World Games. The sample included 562 U.S. special athletes and 1,187 from countries outside the United States. Two percentile range guidelines established by the CDC were used in the study, risk of becoming overweight (85th to 95th percentile) and overweight (at or above the 95th percentile) (Barlow & Dietz, 1998). BMIs were estimated from athlete height and weight measurements taken at Special Olympic health screenings; with overweight criterion defined as 25 kg/m<sup>2</sup> or greater.

The prevalence of overweight and risk of becoming overweight was 3.1 to 4.9 times more likely for U.S. special athletes than for their peers outside the United States. Almost half the U.S. child special athletes (below age 18 years) and over half the U.S. adult special athletes (18 years and above) participating in Special Olympic venues were overweight. Researchers stated that these findings were similar to those for the general U.S. population that have found obesity to be increasing rapidly among children and adolescents (Flegal et al., 1998; Flegal & Triano, 2000). The prevalence of overweight among the 539 child special athletes under age 18 (U.S. athletes n = 119; non-U.S. athletes n = 420) was significantly higher (p < .001) for U.S. participants, who were 2.7 times more likely to be at risk of being overweight and 6.19 times more likely to be overweight.

# Marshall, McConkey, & Moore (2003)

This study was a follow-up of treatment plans for 122 persons

identified as obese or overweight when 464 persons with cognitive disabilities (aged 10 and older) had taken part in one *Health and Social Services Trust* special screening clinic in Northern Ireland. The screening identified 64% of adults (aged 20 years and above) and 26% of children and adolescents (aged 10 through 19 years) as overweight or obese. Of note, individuals aged 40 to 49 that were identified as obese in the screening were found to have significantly higher blood pressure levels than normal weight persons. The results of a questionnaire sent three months after the screening revealed that only 41 persons (34%) had undertaken a weight reduction program, and only 3 persons had lost weight. This finding suggests that screenings alone have limited impact on weight reduction in this population.

The second part of the Marshall, McConkey, and Moore (2003) study evaluated the impact of nurse directed health promotion and weight reduction classes (held for 6 or 8 weeks) on 20 participants. Significant reduction in weight and BMI scores resulted from the program. These findings suggest that caregivers can create more active and healthy lifestyles for individuals with cognitive disabilities by working in tandem with health care personnel. Leading a more active and healthy lifestyle could result in significant weight and BMI reduction for persons with intellectual disabilities.

Braunschweig, Gomez, Sheean, Tomey, Rimmer, and Heller (2004)

This study is representative of cardiovascular health studies

conducted with samples of individuals experiencing cognitive disabilities that include BMI information as descriptive demographic data or subject variables that might mediate or covary results, rather than as a research focus. BMI data reveals obesity prevalence and is important to other types of health-related fitness studies for the target population.

The Braunschweig et al. (2004) study included 48 adults with cognitive disabilities residing in the community. Measures performed included waist circumference, height, weight, blood tests (such as plasma glucose and lipids), and frequency of food consumption. Results indicated that 89% of the participants were overweight or obese, 54% had large waists (large abdominal fat deposits are indicative of possible cardiovascular problems), and participants' eating patterns did not meet current daily-recommended fruit or vegetable consumption guidelines. In this particular study, participants' lipid and glucose levels were within normal limits for risk of hypertension.

# Summary of Prevalence Studies

Table 6 provides a summary of topics investigated and researchers' conclusions. In recent years, health screenings (including hearing, vision, dental, and weight) have emphasized the growing health and fitness disparity between individuals with cognitive disabilities and those without (Harris et al., 2003; Horowitz et al., 2000; Marshall, McConkey, & Moore, 2003; Rimmer, 1994, 2000). The high incidence of overweight and obesity within this segment of the population and links to chronic

Topic - Relationship	Researchers Investigating Obesity Prevalence Topics	Findings Related to Obesity
Varies by etiology	Bell & Bhate (1992); Cronk, Crocker, Pueschel, Shea, Zackai, Pickins, & Reid (1988)	With Downs: (1) Obesity more prevalent; (2) legs tend to be shorter with weakness & difficulty doing activity; (3) Shorter & lighter with severe heart problems
	Rimmer, Braddock, & Fujiura (1992)	%BF in MR not affected by Down's
Obesity related to level of cognitive disability	Fernhall & Tymeson, 1987; Fernhall, Tymeson, Millar, & Burkett (1989); Fernhall, Tymeson, & Webster (1988)	substantially less fit with moderate to severe cognitive disabilities than mild
	Fox & Rotatori (1982); Kelly, Rimmer, & Ness (1986); Kreze, Zelina, Juhas, Garbara (1974); Rimmer, Braddock, & Fujiura, (1993); Simila & Niskanen (1991); Wallen & Roszkowski (1980)	obesity higher with mild to moderate than severe to profound disabilities
	Kreze, Zelina, Juhas, Garbara (1974)	Obesity higher with IQ < 90; Females inverse relationship between IQ & BF%
	Gibson (1997)	Level of MR identified as a factor
Varies with gender	Kreze, Zelina, Juhas, Garbara (1974); Nordgren (1970); Polednak & Auliffe (1976)	Males greater obesity problem than females
	Bell & Bhate (1992); Fox & Rotatori (1982); Frey & Rimmer	Female are more obese than males

Table 6

ura 980)	Gender identified as a factor	Risk of CVD higher in males	Larger skinfold thickness in males with disability; female no significant variance	More persons with cognitive disabilities are obese or overweight than persons without disabilities	Obesity greater with age	More obese in U.S.	Medication identified as significant factor	More obesity in less restrictive settings (community, parents' home); less obesity in institutions	Institutionalized - better blood tests; lower weight & BMI. <i>Group homes -</i> smoked & drank more, exercised the least. <i>Family home -</i> more obese.
(1995); Kelly, Rimmer, & Ness (1986); Rimmer, Braddock, & Fujiura (1992, 1993); Simila & Niskanen (1991); Wallen & Roszkowski (1980)	Gibson (1997)	Rimmer, Braddock, & Fujiura (1992)	Nordgren (1970, 1971)	Bell & Bhate (1992); Burkhart, Fox, & Rotatori (1985); Eichstaedt & Lavay (1992); Jackson & Thorbecke (1982); Rimmer, Braddock, & Fujiura (1993); Rubin, Rimmer et al. (1998); Simila & Niskanen (1991); Staugaitis (1978)	Gibson (1997); Walten & Roszkowski (1980)	Frey & Rimmer (1995); Harris, Fada, Rosenberg et al. (2003) Marshall, McConkey, & Moore (2003)	Gibson (1997)	Cronk, Crocker, Pueschal, Shae, Jachai, Pickens, & Reid (1988); Frey & Rimmer (1995); Rimmer, Braddock, & Fujiura (1993); Rubin, Rimmer, Chicoine, Braddock, & McGuire (1998)	Rimmer, Braddock, & Marks (1995); Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998
			Differs between persons with & without disability		Effect of other factors; - age	- country, region	- drug therapy	- living arrangement	

health problems has become a national area of interest. Recognition of the health disparity between individuals with and without cognitive disabilities prompted the U. S. Surgeon General's *GAP Report* (USDHHS, 2002), and has heightened awareness of the lack of health treatment and maintenance options for persons with cognitive disabilities (Alexander, 2002). Growing interest in the relationship between obesity, genotypes, and clinical conditions was demonstrated in research reviewed and should be more fully explored (Bray, 1975, 1979, 1987); although a small percentage of persons with cognitive disabilities is thought to be effected.

# Methodological Limitations

A relatively small number of investigations has been conducted to study the prevalence of overweight and obesity in persons with cognitive disabilities. Small samples were frequently used when studying individuals with cognitive disabilities. There was a paucity of research conducted on children, youth, and young adults with cognitive disabilities, including comparative and intervention studies.

Methodological inconsistencies (such as measures of body size and composition), differing analysis and measurement techniques, varying criteria values to establish overweight and obesity prevalence, changing MR definitions and conflicting results complicated comparison of studies reviewed. Incomplete descriptions of interventions and participants were also problematic. Replication of studies and generalizability of results could be limited. Persons with IQs too high to be diagnosed with

cognitive disabilities have been included in prevalence studies (such as Kreze et al., 1974).

### Conclusions from Prevalence Studies

The literature reviewed presented overwhelming evidence that obesity was more prevalent in persons with cognitive disabilities than the general population (Bell & Bhate, 1992; Burkhart, Fox, & Rotatori, 1985; Eichsaedt & Lavay, 1992; Jackson & Thorbecke, 1982; Kelly, Rimmer, & Ness, 1986; Rimmer, Braddock, & Fujiura, 1992, 1993; Simila & Niskanen, 1991; Staugaitis, 1978). More females (58.5%) than males (45.2%) with cognitive disabilities were overweight or obese. Individuals with cognitive disabilities residing in the United States were overweight or obese more frequently than their peers from other countries (Frey & Rimmer, 1995; Harris et al, 2003).

Cognitive ability and living arrangement have been found to influence fitness level and prevalence of overweight and obesity in persons with cognitive disabilities, ultimately influencing health. The prevalence of obesity for persons residing in institutions was less than for individuals living in less restrictive settings (such as communitybased group and natural family homes) (Frey & Rimmer, 1995; Rimmer, Braddock, & Fuijura, 1993; Rimmer, Braddock, & Marks, 1995). Persons diagnosed with mild and moderate levels of MR were obese or overweight more frequently than persons with severe and profound cognitive impairments (Fox & Rotatori, 1982; Kelly, Rimmer, & Ness,

1986). Individuals with cognitive disabilities having the highest IQs, within the MR range, and living in family homes were reported as obese or overweight most frequently (Frey & Rimmer, 1995; Rimmer, Braddock, Fujiura, 1992, 1993; Rimmer, Braddock, & Marks, 1995). Researchers theorized that the greater control persons with mild cognitive disabilities, and perhaps some persons within the moderate range, have over their own lives could explain some of the variance in obesity prevalence rates exhibited. These individuals have demonstrated the same poor choices in exercise and nutrition made by persons in the general population (Kelly, Rimmer, & Ness 1986; Rimmer, Braddock, & Fujiura, 1992, 1993).

Literature indicated that level of fitness was relative to degree of disability. Adolescents with cognitive disabilities have demonstrated lower levels of physical fitness on most measures of health-related fitness than their nondisabled peers (Campbell, 1973; Coleman, Ayoub, & Fredrick, 1976a, 1976b; Maksud & Hamilton, 1974; Winnick, 1984; Winnick & Short, 1999). Persons with moderate and severe MR were substantially less fit than individuals within the mild range, with cause for difference inconclusive (Fernhall & Tymeson, 1987; Fernhall, Tymeson et al., 1989; Fernhall, Tymeson, & Webster, 1988; Fox & Rotatori, 1982; Kelly, Rimmer, & Ness, 1986; Kreze et al., 1974; Rimmer, Braddock, & Fujiura, 1993; Simila & Niskanen, 1991; Wallen & Roszkowski, 1980). These findings could affect ability to be active and

exercise, thereby influencing prevalence of obesity and overall health.

A growing interest in the relationship between obesity, genotypes, and clinical conditions was demonstrated in research (Bray, 1975, 1979, 1987). Table 7 summarizes some characteristics of individuals with

Table 7

Characteristics		Study P	articipant	Clinical Condition	ns
	Down	Fragile-X	PDD	Prader-Willi	Non-spec MR
Level of functioning	Х	Х	Х	Х	Х
Short stature	Х			Х	
Orthopedic	Х	Х		Х	
Spina-bifida				Х	
Gastro-intestinal	Х			Х	
Cardiovascular/ Respiratory	Х				
Attention deficit	Х	Х	Х		Х
Hyperactivity		Х	Х		Х
Oppositional				Х	
Behavior/Emotional		Х	Х	Х	Х
Vision/ Strabismus Hearing	Х			Х	Х
Hypothyroidism	Х				
Hypotonia	Х			Х	
Hypothalamus				Х	
Decreased caloric Requirement				Х	
Thick viscous saliva causing tooth decay	Х			Х	

FACTORS OF CLINICAL DIAGNOSES CONTRIBUTING TO OBESITY

*Notes: PDD* = *Pervasive Developmental Disorder; Non-spec* = *mental retardation from an unspecified origin* 

cognitive disabilities having genetic syndromes (such as Down syndrome and Prader-Willi), which may produce physical anomalies that exacerbate obesity (Appendix B).

#### Research Needs Indicated by Prevalence Studies

Factors contributing to the trend toward increased obesity in the general population should be explored and their effect on individuals with cognitive disabilities examined. Individuals with disabilities appear to be influenced by many factors, such as fast food and lack of exercise, in the same manner as their nondisabled peers (Frey & Rimmer, 1995; Harris, Fada, Rosenberg, Jangda, O'Brien, & Gallager, 2003). Research should be conducted into the cause of greater obesity prevalence in persons with disabilities, especially females, when compared to those without disabilities.

Prevalence studies suggested a need to conduct research focused on factors that influence lifestyle, food intake, activity habits (with emphasis placed on excess caloric expenditure), and metabolic disorders. Development of intervention programs with potential to improve health-related lifestyle and reduce percentages of body fat, instead of just weight reduction, is most pressing for children, adolescents, and young adults. Research into validated field and state of the art laboratory methods used to accurately measure body composition in nondisabled individuals, needs to be extended to this population. Although not specific to persons with cognitive disabilities, research into

methods to satiate the appetite should continue.

### Program Development Needs

The efforts of separate disciplines conducting research for persons with cognitive disabilities (such as psychology, special education, sports, nutrition, and medicine) should be marshaled together on behalf of these individuals.

*Education needs*. Findings from prevalence studies support the need for health education. Information should be provided on the importance of what is eaten and how to monitor diet and exercise. An obesity prevention plan for implementation with children at a young age is needed, given the early onset and high prevalence of overweight and obesity this population.

Prevalence studies reviewed support the need to develop simple dietary guidelines to be included in nutrition education materials created for individuals with cognitive disabilities (American Dietetic Association, 1987, 1992; Haring & Sawey, 1984). Dietary treatments alone are ineffective in controlling obesity in all individuals and should be combined with strategies for activity (Wooley & Garner, 1994). Health, nutrition, and exercise education curriculum and programs should be developed that appropriately address the literacy needs of this population. Programs should include illustrated high interest, low reading level health literacy materials geared to children through young adults with cognitive disabilities. Inclusive basic nutrition and health

topics should be included in simple format curricular materials with exercise plans. Self-monitoring techniques should be developed and instructed.

Definitions and tools. In order to provide greater benefit to the population of persons with cognitive disabilities, efforts should be made by researchers to use well-defined study designs, criterion values, measures, and techniques that would encourage comparison and replication of findings. Specific body composition measures (such as body density, body fat percentages, and BMI standards) and techniques should be developed for individuals with mental and physical disabilities, which include clinical and etiological diagnoses (Cole el al., 2000a, 2000b; He, Albertson-Wikland, & Kalberg, 2000; Reilly, Dorosity, & Emmett, 2000). Definitions of overweight and obesity based on this population should be established, with criteria stated, and standardized. The absence of appropriately validated growth, BMI tables, and nomograms for this population and certain phenotypes (such as cerebral palsy and Down syndrome [Cronk et al., 1988]) was noted and should be developed, made available, and widely distributed.

### Weight Loss Interventions

## Overview of Weight Loss Rationale

Historical studies underscored the significant obesity problem in persons with cognitive disabilities (Fox & Rotatori, 1982). Niesworth and Smith (1978) and others revealed that limited activity levels paired

with excessive caloric intake were the major causes of obesity. Rotatori and Fox (1981) suggested that the multiple causes of obesity in adults with cognitive disabilities are similar to those in the general population. Activity levels of individuals with disabilities continue to be lower than for the general population. The high prevalence of obesity among individuals with cognitive disabilities should generate research that approaches the needs of this population.

# Intervention Considerations

Studies that combined exercise and diet to ameliorate obesity in this population, as is recommended for the population at large, were scant. There was also a paucity of investigation into appropriate methods, with established guidelines, for measuring the body composition of this population. Literature reviewed focused on interventions to alter body size in individuals with cognitive disabilities followed two distinct approaches. The first approach explored weight loss (body mass) through behavioral therapy (behavior modification). The second approach shifted slightly toward health-related fitness, including exercise (tone and shape) and its relationship to body composition (percentage of body fat and distribution with health and fitness measurement designations). Challenges were connected to both approaches (Bouchard & Johnston, 1988; Bruch, 1940; Meyer, Eichinger, & Park-Lee, 1987). Lack of social networks and transportation issues limited activity opportunities (Kozub, 2003). An

inverse relationship exists between age and activity, with age related trends being better predictors of activity than motivation (Sallis, Prochaska, & Taylor, 2000; Kozub). A need exists for self-determination training that could enhance the ability of individuals with cognitive disabilities to provide input into choices (including sampling opportunities) for activities of interest (Wehmeyer, 1994). Control and reinforcement issues were linked to behavior modification, while nagging concerns were connected to motor skill ability, poor fitness levels, activity, nutrition, and health issues (Brasile & Hedrick, 1991). Improved health through nutrition and body activity is a fundamental premise of health-related fitness. Intervention programs have met with varying degrees of success or failure, dependent upon motivation, interest, and compliance (Cohen, 1985).

# Behavior Therapy Overview

Research into weight loss using modified behavior therapy techniques in individuals with cognitive disabilities began in the late 1960s (Abramson, 1967; Buford, 1975; Rotatori, 1978; Rotatori & Fox, 1981; Stuart, 1967; Stunkard & Penick, 1979; Wollersheim, 1970). Few of the early studies had control groups or included long-term maintenance and follow-up. Many studies were conducted in institutions or restrictive settings. Behavioral approaches have demonstrated some effectiveness in amelioration of obesity problems with individuals experiencing Prader-Willi syndrome (Altman, Bondy, &

Hirsch, 1978; Heiman, 1978). The long-term effectiveness of weight control indicates a necessary change in lifestyle, while health concerns dictate a need to improve body fat levels.

The first weight loss studies for individuals with disabilities located in the literature search were based on behavior modification therapy and research conducted on individuals without disabilities. The basic ABC elements of behavior modification are: (a) antecedents [events] that prompt an action; (b) the target behavior; and (c) consequences [the result of the actions]. Techniques utilized in behavioral therapy programs included self-monitoring, behavior control, eating reduction (speed, quantity, and type), reinforcement of appropriate behavior, and negative behavior or attitude restructuring (Table 8). Self-monitoring was interpreted as awareness of one's own targeted actions in the environment (such as food eaten and time), which were usually recorded in a diet diary and analyzed with reference to a daily log measure (such as calories or degree of adherence to prescribed program). The antecedent or stimulus that cued the eating response (such as sight of food, the taste, time of day, place, or activity) were recorded and analyzed. Research informs that cues may signal the eating response in persons who are obese, rather than physiological hunger (Schachter, 1971). The theory that a difference existed in the susceptibility of hunger cues between persons with and without disabilities was controversial, yet included in many behavioral weight loss programs.

### Table 8

Element	Explanation	Example
Self- Monitor	Identify Antecedent - stimulus cues to eat	Diet Diary and Daily Log Measure
Behavior Control	Stimulus control - control cue to eat	Examples: keep food out of sight; shop and make only nutritious foods available; limit time and place to eat monitor activities tied to eating and stop automatic eating; avoid dealing with food
	Eating control - change food intake (quantity, type, and speed)	Examples to slow intake: lay utensil between bites; pause during meal; count bites, chews, and swallows
Reinforcement	Consequence - reward for following plan	Social reward (cheer, clap; verbal); Therapist reward (verbal, chart); Token economy (trade for reward); Self- administered reward program
Attitude restructuring	Changing attitudes and behavior permanently	Examples: Change habits; automatic control of stimulus

BEHAVIOR THERAPY WEIGHT LOSS TREATMENT TECHNIQUES

Note: Techniques were based on the "ABC" elements of behavior modification.

# Behavior Modification Strategies

Behavioral treatments to control stimulus included: keeping food out of sight, limitations placed on location and time eaten, closely monitoring or avoiding activities associated with eating, ending automatic eating, careful shopping for home foods, and general avoidance of dealing with food as much as possible. Self-monitoring of external cues provided information about what might promote excess eating. Slowing the intake of food was an unproven technique used in behavior therapy. It was theorized that obese people ate so rapidly that they were full before the brain provided satiety signals, therefore more food was consumed than needed, which caused excess caloric intake and obesity. Behavior therapy techniques to slow eating included: laying utensils on the table between bites, pausing midway through the meal, and sometimes counting bites, swallows, or chews.

Researchers believed that positive reinforcement was a necessary consequence to modify behavior (needed to learn and continue the appropriate behavior). Behavior therapy techniques used as a reward for increasing desired eating behaviors (such as restraining food intake) included positive comments and praise from treatment group peers and the group leader, as well as social rewards from family or other meaningful person or group. The possibility of avoiding future chronic health problems was too distant to be a meaningful reinforcement for individuals with cognitive disabilities. Weight loss and self-satisfaction did not appear to be sufficient to change eating behavior. A formal selfadministered system contingent on weight loss was introduced (such as a reward based on a predetermined number of points). Feelings of accomplishment, competency, and self-esteem were considered part of positive reinforcement (Nicholls, 1984).

Attitude restructuring was considered necessary in behavior modification to avoid setbacks and retreating to old comfortable eating habits. Setbacks encountered were often viewed as lack of self-control

and elicited feelings of guilt, depression, and anxiety in participants. The concept of program flexibility in behavior therapy for weight loss programs was neither considered nor used.

## Behavioral Weight Loss Techniques

Identification of specific individual cues for unwanted eating responses, that could be measured with responses controlled, and individualized rewards to reinforce desired behavior were underlying elements of behavior modification interventions. Social recognition and token rewards were frequently used for reinforcement (Table 9).

Stuart (1967). Stuart's behavioral therapy strategies stimulated interest in their use as a treatment for obesity and provided a model for

### Table 9

Year & Researcher	Weight Loss Program	Criterion & Results
1967 - Stuart	<ol> <li>(1) stimulus cues to unwanted eating response were identified,</li> <li>(2) response was fully detailed,</li> <li>(3) consequences of the response.</li> </ol>	80% who continued treatment lost a minimum of 20 lbs; 30% lost clients 40+ lbs.
1967- Abramson	(1) Therapist reinforcement & (2) Token economy	Intervention flawed - must include eating behavior modification for weight loss.
1970 - Wollersheim	(1) Social reinforcement (group - positive & negative pressure)	Social pressure has no long-term effect.
1979 – Stunkard & Penick	Reviewed behavior modification study outcomes and concluded	Lower attrition rates, reduced psychological effects of diets, long-term results were better

|--|

*Note: These were early studies conducted with persons not having disabilities. The strategies were later employed with persons having cognitive disabilities.* 

future programs. Stuart's systematic plan for behavioral weight loss provided a method to identify unwanted eating stimulus cues with responses and consequences of each cues fully detailed. Unlike earlier blanket approaches, Stuart's program individualized reinforcement strategies to identified eating stimulus and altered (controlled) the probability of having an unwanted eating response. He reported that 80% of his clients who continued treatment lost a minimum of 20 pounds and 30% of Stuart's clients lost more than 40 pounds.

Abramson (1967). This researcher included individualized token economy and social (therapist) reaction as reinforcement strategies in his behavioral therapy weight loss program. Abramson specified that the social reward had to be from a person(s) highly regarded by the participant and the token exchange had to be for something the participant desired. Although his basic weight loss strategies were sound, the intervention strategy he tested was flawed because it did not include modification of eating behavior to obtain weight loss. Participants used temporary extreme measures (such as laxatives) to lose weight in order to obtain the reinforcement desired, instead of practicing selfcontrol.

*Wollersheim (1970).* Wollersheim conducted a 12-week study that used group therapy (therapist and peers) with social pressure (both positive and mild negative) as the reinforcement strategy for weight loss. His study divided 38 participants into two groups, the treatment group [n

= 20], and control group [n = 18]. Participants in the treatment group conducted weekly weigh-ins with individual current and past week's weights announced. The social pressure received in reaction to the weight difference served as reinforcement for weight change. The social pressure treatment group lost a mean of 5.40 pounds while participants in the control group gained an average of 2.39 pounds. At the 8-week follow-up, members of the treatment group had regained an average of 1.86 pounds, indicating that social pressure was effective only while in place and provided no long-term effect on weight loss.

Stunkard and Penick (1979). Researchers reviewed the results of behavioral therapy weight loss studies and made conclusions that were somewhat supported: (a) attrition rates were lower than experienced with traditional methods; (b) psychological effects of dieting were reduced; and (c) chance of long-term maintenance was improved.

#### Behavior Therapy Weight Loss Studies Reviewed

Early behavioral weight loss studies conducted on persons concurrently diagnosed with cognitive disabilities and schizophrenia are included (Harmatz & Lapuc, 1968; Moore & Crum, 1969; Upper & Newton, 1971). Table 10 provides a brief chronological overview of behavior modification weight loss intervention studies with individuals experiencing cognitive disabilities that are included in the more in-depth narrative review of literature.

Year & Researcher	N, Sex, Level	Weight Loss Program	Criterion & Results
1968 - Harmatz & Lapuc	21 males (age 29-48 yrs). Mild MR &	I = 6 wk (F = 4 wk) 3 Random Treatment Groups: (1)	Criterion: Dietary staff identified as overweight. Group results:
	schizophrenia; institutionalized	response cost, (2) group therapy, (3) supervised diet at mealtime All groups: \$5/wk, reduced 1800 calorie daily diet, weekly weigh-ins.	<ol> <li>Mean 4% loss with 7% total loss at follow-up; (2) Mean 2% loss; maintained at followup;</li> <li>no weight loss</li> </ol>
1969 - Moore & Crum	1 female (age 24 yrs). MR (level not reported) & schizophrenia; institutionalized	I = 5 mo (22 wk), 1 mo (4.3 wk) fade, (F = 0). Case study. Included operant contitioning; researcher as social reinforcement, weekday weigh-ins, charted.	Criterion: Doctor's care for weight problem; on low calorie diet. Note: Initial trip home regained 1/2 lb. a day for 1 wk; Total weight loss = 35 lbs.
1971 - Upper & Newton	2 males (aged 36 & 45 yrs). MR (level not reported) & schizophrenia; institutionalized	<ul> <li>I = 25 &amp; 28 wks for loss goal (F = 0)</li> <li>1500 calorie diet plan ineffective;</li> <li>Revision: added token economy</li> <li>for 3 pound weekly weight loss</li> </ul>	Criterion: inability to lose wt Subject A - began at 263 lbs. lost 63 lbs. in 28 wks Subject B - began at 201 lbs. lost 31 lbs. in 25 wks
1972 - Foxx	1 female (aged 14 yrs); MR mild; limp, right leg. sheltered workshop; institutionalized	<ul> <li>I = 27 wk, 15 wk fade (F= 0)</li> <li>12 wk diet &amp; long-term reinforcer;</li> <li>15 wk intervention added with</li> <li>weekly weigh-in, social reinforcer &amp;</li> </ul>	Criterion: Obese, doctor's care, diet & long-term reinforcement not effective; Revised: added S reinforcer, weekly cateen trip

Behavior Therapy Weight Loss Studies

Table 10

		token economy (for 3 lb/wk loss).	alone for soft drink; (3) diet & opportunity to steal or beg food remained in effect. Lost 79 lbs.
1975 - Buford	15 students (3 dropped out (aged 6-21 yrs). MR trainable-moderate; At school; family home	<ul> <li>I = 8 mo (35 wk), (F = 0); School nurse &amp; counselor conducted ; nutrition class, meal checklist, eating guide, exercise, reinforcer, &amp; parental participation.</li> </ul>	Criterion: Researcher identified Mean wt loss: 8.5 lbs.
1975 - Foreyt & Parks	3 females (19-36 yrs) MR severe (1Q 26-35); Daycare-training facility; family home	<ul> <li>I = 11 wk (F = 29 wk)</li> <li>Monitored food grp intake with colored tokens); daily weigh-in; reinforcer \$.50/wk for 1 lb. wt loss;</li> <li>Parent eating stimulus control.</li> </ul>	Criterion: Dr exam & >10% over ideal wt; Finding: Parental control played key role in weight loss. Mean wt loss: 8.5 lbs. Added mean wt loss: 15.21 lbs.
1975 = - Joachim & Korboot	32 (16 M, 16 F); adults (mean age 34.55 yrs); MR mild; institutionalized	<ul> <li>I = 8 wk (F = 8 wk); 4 Groups, split</li> <li>(1) Self-monitoring (2/day weigh-in, posted &amp; not); instructed to lose wt &amp; not; (2) Therapist reinforcement weekly grp meetings (1/2 of 4 grps).</li> </ul>	Criterion: Obese, not provided Finding: Significant positive effect related to researcher contact; Mean weight loss of 9.58 lbs. across all groups.
1977 - Joachim	1 female (32 years) MR mild; institutionalized	I= 38 wks + 8 wk baseline (46 wks), (F = 46 wk); Self-monitoring (4 X/ day weigh-ins, daily food diary) & structured weight loss program	Criterion: not provided Wt Loss: 38 lbs. At follow-up had regained 37 lbs.
1977 - Gumaer & Simon	11 (3 M, 8 F); (aged 11 - 21 yrs); (2 dropped)	I = 14 wks (F = 3 mo); Self control weight, loss & control	Criterion: not provided Mean weight loss for 9 that

	MR trainable/moderate & non-communicative; Conducted at school. Lived at home.	program; Group education & counseling 30 min. 3 x / wk; Reinforcement from researchers & schoolwide. Parent participation.	finished mean 11.8 lbs. At follow-up 8 students lost additional mean 3.75 lb.
1978 - Altman, Bondy & Hirsch	2 females (13 & 18 yrs) MR mild - moderate & Prader-Willi. Lived in family & group home.	<ul> <li>I = 19 mo (82 wk) &amp; 13 mo (55.9 Criterion: not provided; No wk), (F = 3, 6, 9, &amp;12 mo). 3 phases: loss with self-monitor, wt loss self monitor; positive reinforcement; with reinforcement, wt loss removal of reinforcement.</li> <li>Wt loss 65 &amp; 30 lbs retained</li> </ul>	Criterion: not provided; No wt loss with self-monitor, wt loss with reinforcement, wt loss continued after reforcer removed Wt loss 65 & 30 lbs retained.
1978 - Heiman	2 (15 & 17 years). MR, mild-moderate & Prader -Willi; institutionalized.	l = 12 weeks (F = 3 mo [12.9 wk]). Social reinforcement (verbal, notes, light affection); Token economy	Criterion: not provided Younger participant lost 22.13 lbs. & older lost 13.28 lbs.
1979 - Behavior Therapy Program developed Rotatori & Switzky (note)	Individuals with cogni- tive disabilities	I = 14 wk; M = 5 wk (F $\approx$ 19th wk) Developed sequential 7-step behavior therapy program; 1 to 2 meetings per wk maintenance to review and reinforce techniques	Self-monitor; stimulus control; Control behaviors (food quantity, speed); manipulate emotional responses to control over-eating; use excess calories; reinforcers (social & self)
1979 a - Rotatori & Switzky	18 (Mean 17.8 yrs) MR, moderate public school family home	<ul> <li>I = 14 wks; M = 5 wk (F = 16 wk)</li> <li>Compared sequential instruction</li> <li>delivery 3 X/wk (live &amp; recorded)</li> <li>3 groups (live, recorded, &amp; wait-list</li> <li>control). Reinforced 1 lb/wk loss</li> </ul>	Criterion: not provided Findings: no difference in technique delivery; Mean wt loss = 9.73 lbs.
1979 - Rotatori, Fox & Switzky	6 (mean age 17.5 yrs) MR, mild - moderate &	I = 14 wk; M = 5 wk (F = 16 wk) (Rotatori & Switzsky [1979] plan)	Criterion: not provided Mean wt loss = 10.37 lbs. end,

	Down syndrome		maintenance 3.95 lbs., follow-up 3 persons continued wt loss (mean 9 lbs.).
1979 - Rotatori, Parrish & Freagon	6 (aged 6-21 yrs) MR, mild to moderate Conducted at school. family home	1 = 7 wks; M = 5 wk (F = 12th wk) School nurse; School breakfasts & lunches modified. (Rotatori & Switzsky [1979] plan).	Criterion: not provided Mean weight loss 3.70 lbs. at end of intervention.
1980 <b>e</b> - Rotatori, Fox, & Switzky	18 adults MR, mild; semi-independent residental care facility	I = 7 wk; M = 5 wk (F = 10 wk) (Rotatori & Switzsky [1979] plan) 2 groups (treatment & control)	Criterion: not provided Finding: treatment group lost mean 3.6 lbs. at end of plan. No difference during maintenance; At follow-up treatment group lost mean 4.4 lbs & control group gained mean 2.2 lbs
1980 = - Rotatori, Switzky, & Fox	18 adults MR, Mild; Semi-independent residential intermediate care facility	<ul> <li>I = 7 wk; M = 6 wk (F = 10 wk)</li> <li>2 groups (treatment &amp; control);</li> <li>Self-monitored homework (food log, daily weigh-ins); 3 monetary group reinforcers for weekly 1 lb.wt loss</li> <li>&amp; turning in homework; Met once weekly (50 min.) for technique instruction using various methods</li> </ul>	Criterion: not provided Mean wt loss treatment groups: 3.6 lbs during intervention (no significance between monetary reinforcement groups; control group gained mean 1.8 lbs.
1980 a - Rotatori & Fox	30 (18.2 mean yrs) MR, moderate Conducted at school	<ul> <li>I = 14 wk; M = 5 wk; School nurse,</li> <li>3 groups: Rotatori &amp; Switzky plan,</li> <li>social weight loss (met 2 x / wk),</li> </ul>	Criterion: not provided Mean wt loss: 10.27 lbs. Weight loss was higher in behavioral

		wait-list control group	than social intervention group. Weight-list control group gained 4.42 lbs. (trend in this type grp)
1982 - Fox, Rotatori, Macklin, Preschool children (3 to & Green (note) 6 yrs); MR & autism	cklin, Preschool children (3 to (note) 6 yrs); MR & autism	Moniter snacks, stimulus cues, positive reinforcement, parents	Desire to lose wt & preferred reinforcement important.
1982 <b>-</b> Jackson & Thorbecke	12 females (aged 16 to 34 yrs) MR, moderate (11), severe (1) Conducted at school. family home	<ul> <li>I = 14 wks (F = 13, 26, &amp; 52 wk)</li> <li>Self control, reinforcement, parent involvement; monitoring; education.</li> <li>2 groups: control &amp; treatment.</li> <li>SpEd teacher was therapist.</li> <li>3 weight dependent varible measures: kg lost, % wt loss, reduction quotient.</li> </ul>	Criterion: > 10% overweight Mean weight loss in kilograms - Treatment grp 9.19 lbs. end of intervention, follow-up 13.78 lb. Control group loss .93 lb. end, 1.30 lb. at follow-up. Success may be due to parental control of food & monitoring.
1983 - Fox, Burkhart, & Rotatori (note)	28 (mean age 30.3 yrs) MR, moderate (mean IQ 50.6); sheltered workshop	Observation of eating habits at meatime - compared eating rate & time meal lasted. 2 groups (obese & non-obese).	Criterion: body weight & triceps skinfold; Findings: total meal time, caloric intake, & eating rate did not significantly differ between groups.
1984 - Fox, Haniotes, & Rotatori	16 M & F (aged 20-38) MR, moderate; sheltered workshop; lived with parents	<ul> <li>I = 10 wks; M = 5 wks (F =52 wk)</li> <li>2 treatment groups: behavioral therapy, added peer buddy</li> <li>reinforcement; Parents monitored included instruction &amp; practice.</li> </ul>	Criterion: >10% over desired wt Difference in weight loss between groups was not significant. At 1-year follow-up 37.5% (3 males & 3 females) retained loss.
1985 = - Cottrell	16 adolescents (10M, 6F)	16 adolescents (10M, 6F) I = 7 wk; M = 8 wk $_{,}(F = 12 \text{ wk})$	Criterion: Placement on calorie

	MR, moderate to severe Residental state facility	2 groups: treatment & control. Intervention: modeling, group therapy, & therapist reinforcement.	restricted list. Height, weight, BMI, skinfold (excluded). End mean wt loss T=5.89 lb C=5.44.
1985 - Fox, Rosenberg, & Rotatori	15 (aged 27-29 yrs) MR, moderate; sheltered workshop; lived with parents	I = 10 wk, (F = 26 wk) 2 groups: parental & minimal parental involvement (eating & activity monitored). Behavior therapy & self-reinforcement.	Criterion: not provided; Grp 1 wt loss greater than grp 2. Strong correlation parent to wt loss. At follow-up mean regain was grp 1 = 3.9 lbs & grp 2 = 6.3 lbs
1986 ∎ - Rotatori, Fox, Matson, Mehta, Sudha, et al.	17 adolescents MR, trainable	<ul> <li>I = 21 wk; 3 groups: 1 treatment,</li> <li>&amp; 2 controls (normal weight &amp; weight list). Treatment: self-monitoring, stimulus food cue elimination, exercises, &amp; changing snack habits (included substitution of activity).</li> </ul>	Criterion: not provided Height, weight, triceps skinfold, abdominal circumference, & diastolic blood pressure as DVs. Findings: 2 control groups gained weight, treatment group significant loss in wt & DVs.
1986 - Rotatori, Zinkgraf, Matson, & Fox	13 adults (age 26-36 yr) MR, mild to moderate	<ul> <li>I = 12 wk; M = 10 mo (43.3 wks), (F= 52 wk, 2 grps); After intervention &amp; maintenance of weekly weigh-ins, 2 grp post-maintenance plans assessed (couseling &amp; wt control).</li> </ul>	Criterion: not provided Both post-treatments were effective; At long-term follow-up without maintenance, weight had been regained.
1987 <b>=</b> - Norvell & Ahern	I3 adults MR, mild to moderate at sheltered workshop	I = 10 wk Behavior therapy 2 groups: treatment & control (treatment then introduced to control group)	Criterion: > 15% overweight Mean wt loss: 5.29 lbs. Findings: Mean wt loss for treatment group was 4.41 lbs., control group 0.33; Mean loss

			for combined groups 5.52 lb. Worksite strategy effective.
1990 = - McCarran & Andrasik	8 adults MR, borderline to mild & cerebral Palsy 3 IQs were above 78)	I = 14 wk (F = 1 yr) 2 groups: treatment (Help), & control (No help). Effect of parental or caretaker involvement on weight loss was assessed.	Criterion: > 15% overweight Findings: Help group lost mean of 5.5 lbs (follow-up retained 3.4 loss), control lost mean 2.7 lbs. (follow-up regained 1.1 lbs). Parental/caretaker help strategy was not statistically beneficial.
1997 - Schloss and Alper	<ul> <li>3 males (aged 16-17 yrs) I = 5 wk (F = 60 days)</li> <li>MR &amp; mentally ill (level Self-monitoring &amp; rein not provided).</li> <li>Treatment: Use of RD Treatment: Use of RD Lived in group home;</li> <li>Attended public school of meals. (Special edu planned)</li> </ul>	I = 5 wk (F = 60 days) Self-monitoring & reinforcement. Treatment: Use of RDA (including calories) to plan & shop for 3-days of meals. (Special educators planned)	Criterion: not provided After follow-up participants continued to successfully plan meals at RDA & calories for age & gender.
Notes: = = Control group; Gen Program: I = interven	<ul> <li>Control group; Gender - M = male, F = female; Groups: C</li> <li>Program: I = intervention, M = maintnance, F = follow-up</li> </ul>	Notes: ■ = Control group; Gender - M = male, F = female; Groups: C = control, T = treatment; Program: I = intervention, M = maintnance, F = follow-up	

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### Harmatz and Lapuc (1968)

Researchers conducted a 10-week study (6-week treatment and 4week follow-up) with 21 institutionalized males diagnosed with coexisting mild cognitive disabilities and schizophrenia. Information on daily activity and medication that might affect weight were not provided. The criterion for overweight was dietary staff identification. The effectiveness of three behavioral interventions on weight loss was compared in this study. All participants were placed on restricted 1800-calorie diets, received weekly \$5 allotments to spend at their discretion, and attended weekly weigh-ins. Participants were randomly assigned to one of three treatment groups: (a) response cost, (b) group therapy, or (c) diet supervised at mealtime only. The response cost group lost the greatest amount of weight (7% at follow-up), while the group supervised at mealtime only had no weight loss. No long-term follow-up was reported.

Response-cost group participants were the only persons that could lose their weekly financial allotment. Failure to show weekly weight loss resulted in a \$1 loss, plus their weekly \$5 allotment, which was not restored until individual weight fell below the previous weigh-in amount. The response-cost group participants lost an average of 4% of their original weights with a 7% loss at follow-up.

Weights were taken weekly and posted on a wall chart, followed by group discussion sessions focused on reasons weight was or was not lost for individuals assigned to the behavior therapy group. Therapist

reinforcement consisted of positive remarks for weight loss and encouraging comments for no loss. Therapy group participants averaged a 2% percent weight loss that was maintained at follow-up.

The daily 1800-kilocalorie restricted diet for the supervised at mealtime only group was split into three reduced portion meals. Food intake outside meal times was not supervised and snacking between meals was possible. Therapist reinforcement at weekly weigh-ins was a neutral voice whether weight was gained or lost. The meal-supervised group did not have a weight loss.

### Moore and Crum (1969)

The case study included one institutionalized adult female with concurrent diagnosis of chronic schizophrenia and cognitive disabilities (level unreported). The subject had been placed on a low-calorie diet by her doctor, but was unable to control her weight. Information on medications that might influence weight was not reported. Inability to control weight was apparently the overweight criterion for placement in the weight loss study. Literature noted that daily activity consisted of aimless wandering around a ward, sitting and rocking vigorously in a chair for hours, silly laughing, occasional agitation with incoherent speech in apparent response to voices heard, and ideas of being God or the Queen of England.

After noting the subject's need for acceptance and social approval, frequent attention and social praise were used by the researchers as

reinforcement for weight loss. The researcher met the participant on weekdays in a weight room for approximately 5 minutes to weigh her, post weights on a wall chart, and provide appropriate reinforcement. After two-weeks of successful operant conditioning the participant reported alone for weighing.

The 5-month weekday intervention was followed by a one-month fade (with visits on an underdetermined, but less frequent basis). A 7day trip home after 8 weeks of intervention resulted in 3½ pounds being regained (averaging 1/2 pound per day for the 7-day visit). Self-control was demonstrated on the next trip home 8 weeks later, when no weight was regained. The participant lost 35 pounds during intervention. No follow-up information was reported.

### *Upper & Newton (1971)*

Two institutionalized adult males (aged 36 and 45) diagnosed with chronic paranoid schizophrenia and cognitive disabilities (level not reported) participated in this behavioral weight loss study. Daily activity was not reported, however, Subject A had been institutionalized almost continuously for 18 years and Subject B for 12 years. Information on medications that might affect weight was not provided.

Participants were initially unable to lose weight on a 1500 calorie per day programmed reduction diet. A token economy reinforcement plan for weight loss of 3 pounds per week was added to the calorierestricted diet. Tokens were exchanged for privileges individualized for

each participant. Length of program was dependent upon weight loss goal. Subject A lost 63 pounds in 28 weeks (from 263 to 200 pounds). Subject B lost 31 pounds in 25 weeks (from 201 to 170 pounds). No follow-up information was provided.

# Foxx (1972)

A 42-week weight loss case study was conducted with one female institutionalized adolescent (14 years of age), classified with mild cognitive disabilities and a noticeable right leg limp. Criterion for obesity was the inability to lose weight sufficient to have orthopedic surgery. During the first 12 weeks in the study, caloric intake was restricted and only low-calorie food purchases were allowed during canteen trips. Initial long-term reinforcements promised for weight loss (future leg surgery and new clothes) did not provide sufficient motivation. Stimulus cues hampering weight loss efforts identified as: (a) unchecked eating during trips home, (b) frequent canteen stops on the way back from work to beg or steal food, and (c) stealing food on the ward when opportunities arose.

The treatment program was revised to include 15 weeks of social recognition (researcher contact) and token reinforcement (a canteen trip for a minimal 1.5 weekly weight loss at weigh-ins). The participant lost 79 pounds during the study. No follow-up was reported. Researcher phase-out occurred during the 15 weeks immediately following the intervention's completion.

# Buford (1975)

The researcher was a counselor and school nurse who conducted an 8-month weight loss study with 15 students (aged 6 to 21 years) in a public school setting. Three participants did not complete the treatment program. Participants were classified with trainable, moderate cognitive disabilities. The intervention included self-control techniques and group therapy. The researcher identified potential participants needing to lose weight, who were recruited by sending a class permission slip to parents that explained their child's need to reduce weight, time required to complete the intervention, and effort required. The study lasted for a school year, requiring extensive time and personnel. Parents and students received education and motivational reinforcement.

The intervention program included a daily 30-minute diet class that met before lunch each day, followed by participants going through the lunch line together. The cook and physical education teacher were integral parts of the intervention. The cook tried to modify school menus by reducing starchy carbohydrates and fat while increasing availability of fruits and vegetables. The cook, in concert with parents (who filled out a forbidden food checklist), attempted to reduce participants' daily overall caloric intake of 1,100 to 1,200 calories, with age and size adjustments. The physical education teacher emphasized individualized exercise programs, although some participants were able to take part in only very mild activities. The researcher (school nurse-counselor) maintained

individual evaluation sheets with recorded daily weights, health status, and indications of skill demonstrated in selecting appropriate foods.

Parents were reinforced monthly, with a steak dinner for two at a local restaurant, for the weight lost by their children. Parent meetings were poorly attended and individual parent conferences were held as needed to discuss behavioral weight loss progress, techniques, exercise, dietary requirements, eating patterns, reasons for needed weigh loss, and individual problems and successes. The researcher indicated that parents of the most obese children were the least cooperative and unmotivated during the intervention.

Class activities included daily weigh-ins, filling out food logs, watching films, discussing good eating habits, playing games to increase knowledge about food, meal planning, cooking, and exercising. Appropriate reinforcement for participant weight loss included planning and preparing their own meals, occasional extra swim time, individualized exercise and reinforcement, nutrition classes, parental support, and a meal checklist to use as an eating guide.

The 15 participants that began the study attained an average 8.5 pound weight loss during the program. The 12 participants that completed the program lost an average of 10.4 pounds. Although the school continued the program the following year, the long-term effects of the program were not reported.

### Foreyt and Parks (1975)

Three obese adult females with severe cognitive disabilities were participants in this 11-week behavioral weight loss program. Criterion for inclusion in the study was a doctor's exam with obesity designation and being identified as 10% above ideal weight on the 1959 Metropolitan Life standardized weight chart. Participants, aged 19, 21, and 36 years, began the interventions with weights of 126, 161, and 243 pounds. Individual IQs were 26, 30, and 35. Participants lived at home with their families and attended a daycare-training center for individuals with cognitive disabilities.

A 13-week baseline period preceded the 11-week intervention with a 29-week follow-up. Participants were weighed each morning with weights posted on a large chart. Self-control was the behavior weight loss strategy used. The behavior weight loss program included: (a) selfadministered colored tokens used to guide balanced diets [calorie counting was eliminated and parents were informed of foods eaten daily with food group exchanges represented]; (b) daily weigh-ins posted on a large chart; (c) payment of \$.50 per week for a minimal one pound loss; and (d) a parent weight loss guide [explaining course of weight change, eating habits, balanced diet and its importance, use of tokens, weight loss hints, and simple low-calorie recipes] that explained the intervention and provided suggestions to gain control of their children's eating practices in their home environment.

Participants lost an average of 8.5 pounds (range 4.5 to 11) during the intervention. At the 29-week follow-up, participants had continued to lose weight, with a total mean loss of 15.2 pounds (range of 5.75 to 21.5). Foreyt and Parks concluded that parental involvement in the intervention played a role in participants' weight loss. The box of tokens used daily, morning posted weigh-ins, verbal praise of weight loss, and monetary consideration were influential. The person losing the most weight was the most interested in money.

### Joachim and Korboot (1975)

An 8-week study (with 8-week follow-up) was conducted with 32 (16 male and 16 female) institutionalized obese adults diagnosed with mild cognitive disabilities. The effects of two variables (self-monitoring and researcher contact) on weight loss were investigated. Participants were randomly divided into four groups of 8; each group was then halved.

Treatment received by the original groups included: (a) group A weighed and recorded their own weight on personal cards with supervision, before breakfast and evening meals. Participants were instructed to lose weight by using any means available; (b) group B received the same treatment as group A, without instruction to lose weight; (c) group C participants weighed themselves like group A, without recording; (d) control group D did not receive any intervention. One-half of participants from each group attended 20-minute weekly meetings

with the researcher and experienced group socialization: (a) group A discussions focused on weighing, recording, and reducing weight; (b) group B discussions focused on weighing and recording weights; (c) group C discussed weight loss progress; and (d) control group D discussed neutral topics unrelated to weight.

Mean weight changes were provided for the researcher discussion and intervention only groups. A significant effect was seen in the relationship between weight loss and researcher contact; a minimal effect occurred with self-monitoring. Mean results for researcher discussion groups with socialization included: (a) group A, loss of 7.83 pounds during intervention and 6.6 at follow-up; (b) group B's weight loss was largest (twice daily posted weigh-ins, without instruction to lose weight) with 16.3 pounds lost during treatment and 11.6 at follow-up; (c) group C, 6.55 pound loss during treatment and 1.7 at follow-up; and (d) group D, 7.55 pound loss during intervention and 4.25 at the follow-up. Mean weight change results for the groups without researcher contact were: (a) group A, lost 0.08 pounds during the study and loss of 1.4 at follow-up; (b) group B, gain of 0.52 pounds during study and gain of 1.7 at followup; (c) group C, gain of 6.37 pounds during study and gain of 13.9 at follow-up; and (d) group D, gain of 8.4 pounds during study and gain of 8.4 at follow up.

# Joachim (1977)

The case study included one institutionalized adult female

experiencing mild cognitive disabilities. The structured weight control program included eight phases and spanned 46 weeks. Phase A was an 8-week baseline procedure followed by a 38-week intervention. The intervention included self-monitoring, recorded weigh-ins 4 times per day, completion of a food log with time and circumstance, and weekly interviews to discuss weight loss strategies. The food log was discontinued at the end of phase B. Phase C included 4 recorded daily weigh-ins with weekly therapist contact. During phase D, 4 unrecorded weigh-ins occurred and therapist contact continued. No weigh-in procedures occurred during phase E and therapist was discontinued. The phases were then reintroduced in a backward flow beginning with Phase D. During the final week of intervention, the participant was weighed daily.

The participant lost 38 pounds during the intervention, with phase B accounting for the greatest weight loss. The researcher noted that the participant was reluctant to continue the weight loss program when it ended. The rigor of a long-term treatment program for obesity that includes weighing 4 times a day and a daily food dairy is an unrealistic expectation for most individuals. The participant had regained all weight except one pound at the 46-week follow-up. This type intervention demonstrates that weight loss is possible but may not be retained without a realistic lifestyle change and maintenance plan.

### Gumaer and Simon (1977)

A study similar to Buford's (1975) was conducted in a public school setting by a school nurse and counselor. The 14-week self-control behavioral weight loss program began with 11 (3 males and 8 females) participants aged 11 to 21 years. Participants were diagnosed with trainable cognitive disabilities (IQs ranging between 25 and 55) with receptive and expressive communication problems. Participants ranged in height from 53 to 65 inches with beginning weights between 117 and 219 pounds. Study participants had been referred to the school counselor for help in controlling their minimum 20-pound excess weight problems.

The intervention included group counseling and schoolwide reinforcement for self-controlled weight loss. Participants received instruction and counseling from the nurse 30-minutes, two times per week (Mondays and Wednesdays). Instruction included social and selfhelp skills related to proper nutrition and dietary patterns. Participants' communication problems necessitated the use of picture cards with images of fat and lean people to cue preferred body types. Mealtime eating habits and overeating were targeted for change. To provide opportunity and practice in making nutritious meal choices during lunchtimes in the school cafeteria, students could request fruit and low calorie vegetables as substitutes for high calorie starches and dessert. Students were taught physical exercises to burn excess calories and

encouraged to increase their physical activities (such as ride bicycles and take walks).

The counselor met with students for 30-minutes each Friday for weigh-ins and discussion. Students charted weight loss by coloring in pounds lost on thermometer charts. Immediate public praise (hand clapping and verbal) from peers and counselor was reinforcement for a minimal one-half pound weight loss demonstrated at weekly weigh-ins. Student participants achieving weekly weight loss were given a card for their classroom teacher, which prompted praise and special activities or snacks. Student participants that did not lose weight were given a note for their parents explaining their child's lack of progress and no praise was provided. Long-term schoolwide reinforcement provided participants with the opportunity to model in a year-end fashion show that highlighted their successful individual efforts to control or lose weight. Teachers commented on the generalization of participants' cooperative attitudes into all school activities and noted increased interaction and participants helping each other.

Parental participation included attendance at 4 parent meetings, held every other week during an 8-week period. Parent support was high with each study participant having at least one parent at every meeting. This finding conflicts with Buford's (1975) reported results. Parents also helped their children fill out food logs and provided home reinforcement.

Mean weight loss for the 11 students beginning the program was

7.9 pounds. The two individuals that did not complete the intervention gained weight (1 male + 6 pounds, 1 female + 13). The weight change range for all participants was +13 to -30 pounds. The 9 students completing the program lost a mean of 11.8 pounds, with one person losing 30 pounds. The 3-month follow-up revealed a continued weight gain for the 2 students that did not complete the intervention (mean gain of 16 pounds at follow-up with a total mean gain of 26.5 pounds). Eight of the nine participants that completed the intervention were available at follow-up, and demonstrated an additional mean loss of 3.75 pounds; losing a mean of 15.5 pounds during the intervention and follow-up periods. Gender and level of cognitive disability did not appear to effect weight loss.

Researchers concluded that introduction of a similar school program during the early years could assist individuals with cognitive disabilities in forming healthy habits that could aid the control of excess eating and stabilize weight in this population. The early intervention process could be a move toward ameliorating the tendency toward obesity and risk of developing chronic illness at an early age for children and adolescents with cognitive disabilities. Most literature is supportive of researchers conclusions (Sherrill, 1998a, 1998b; Insel & Roth, 2004; USDHHS, 1980, 1996, 2002; Van Itallie, 1979).

# Altman, Bondy, & Hirsch (1978)

A study with varying intervention lengths (19 and 13 months) was

conducted with two female adolescents (aged 18 and 13 years old) having concurrent diagnoses of Prader-Willi syndrome and cognitive disabilities (older with mild, younger with moderate MR). The older participant lived in a group home and the younger lived with her parents. The program consisted of three phases: (a) phase one, self-monitoring calories, weight, and exercise; (b) phase two, positive reinforcement for program elements, weight loss, and lowered caloric intake (food selection and exercise were reinforced); and (c) phase three, maintenance of self-controlled lower caloric intake with faded reinforcement. The final fade step was necessary to provide participants an opportunity to independently practice desired behaviors. The program's elements were introduced gradually to each participant, to ensure success. Both subjects lost weight (43 and 19 pounds) during the intervention treatment (phase 2). Both participants continued their weight loss (22 and 11 pounds) during maintenance (phase 3).

A review of study results showed that self-monitoring alone (phase 1) did not prompt weight loss in either participant. The addition of reinforcement, contingent upon reduced calories and weight loss, produced substantial weight loss in both participants. When the contingent reinforcement was removed during phase 3 of the program, weight loss continued. Perhaps the weight loss, itself, became the reinforcement for both participants. The older participant reduced her weight from 111 to 80 kilograms in 19 months; while the younger

participant's weight changed from 55 to 39 kilograms in 13 months. Maintenance of weight was seen in the older participant at 3, 6, and 9month follow-ups, no further follow-up occurred. Weight loss was maintained by the younger participant at 12-month follow-up. *Heiman (1978)* 

Two institutionalized participants (aged 15 and 21 years) having concurrent diagnoses of mild cognitive disabilities and Prader-Willi syndrome participated in a 12-week study with follow-up. The program of behavioral therapy included several techniques (such as selfmonitored weight, exercise, and reinforcement contingencies). Social reinforcement for weight loss included three components: (a) verbal praise and affectionate attention from the ward staff; (b) individual notes from the staff physician, which were provided to the ward staff to be given to participants; and (c) a token economy system, with tokens presented immediately after seeing weight loss on the scale. Tokens could be exchanged for individualized reinforcers kept in each participant's storage area. The younger participant reached ideal weight loss by losing 22.13 pounds, which was maintained at the 3-month follow-up. Although the weight loss program was shorter for the older participant, 13.28 pounds were lost and maintained at follow-up. Systematic Behavior Therapy Weight Control Program

Rotatori and Switzky (1979) developed a systematic weight control program that followed applied behavior modification therapy techniques

developed previously by behavioral theorists (Abramson, 1967; Stuart, 1967; Wollersheim, 1970). The efficacy of the program was investigated by a series of research studies (Rotatori, Parrish, & Freagon, 1979; Rotatori, Fox, & Switzky, 1979, 1980; Rotatori & Fox, 1980, 1981; Fox, Switzky, Rotatori, & Vitkus, 1982). The original program spanned 19 weeks: 14 weeks of behavioral intervention followed by 5 weeks of maintenance and follow-up. Rotatori was involved in many published behavioral therapy weight loss programs until 1986.

Seven behavior modification strategies were included in the program: (a) self-monitoring weight and food intake [using daily food and weight logs]; (b) stimulus control by food cue elimination [such as eating in one place and one helping only]; (c) behavior control strategy of reducing the food quantity intake [meals with one portion of average size and limitation of snacks]; (d) behavior control strategy of reducing the rate of eating [slower eating, chewing food completely, pausing midway during meals, and putting down utensils between bites]; (e) manipulation of emotional responses to discourage the urge to overeat [such as substituting talking on the phone or listening to music for eating]; (f) expenditure of excess calories using exercise [calisthenics and walking instead of riding]; and (g) reinforcement [1] external social rewards [such as researcher, peers, group, parental, and teacher), and [2] selfreinforcement with activity rewards for weekly weight loss of one pound and [3] self-recording (points earned were exchanged for individualized

activity rewards such as playing a card game or watching television). The 5-week maintenance plan included weekly or biweekly behavior technique review sessions with continued reinforcement.

Too many studies related to obesity in individuals with disabilities have been undertaken, by Rotatori and Fox with their associates, to be reviewed in this dissertation. Many of their studies have followed behavior modification techniques and a sampling of their studies is presented with some left for future reviews (Rotatori, Fox, & Wicks, 1980; Rotatori, Switzky, & Fox, 1981a, 1981b, 1983). Their many publications have attempted to explain and provide weight control techniques for individuals with learning disabilities (Rotatori, Fox, & Mauser, 1982) and cognitive impairments (Rotatori, Fox, Litton, & Wade, 1985). *Rotatori and Switzky (1979)* 

The described behavioral weight loss program was explained to parents and implemented with 18 teenagers (mean age 17.8 years) diagnosed as moderately cognitively impaired that attended public high school and lived at home with their parents. Participants were divided into three method of instruction groups (two behavioral and a control): (a) live instruction only, (b) researcher playback of taped group one instructions, and (c) wait-list [informed that the other groups were full and they were on a list for the next available spot and to attempt weight loss on their own]. The 14-week study compared instructional delivery techniques (in-vivo versus taped). Sequential and systematic

instructional sessions were held 3 times per week with behavior modification techniques demonstrated and practiced.

Participants were provided self-reinforcement opportunities for engaging in aspects of the program that were rewarded with points redeemable for individually tailored contractual activity rewards (such as bowling, short field trips, or a visit to a friend's house). The reinforcement plan was the same for both intervention groups. Points for rewards were earned at school and at home for completed daily logs and a minimal one pound weekly weight loss. The wait-list control group was weighed weekly with verbal praise given for weight loss. A 5-week maintenance program with reinforcement and twice-weekly sessions occurred for both treatment groups. The maintenance sessions included videotaped techniques and homework log review. At the 16-week followup, no significant difference in weight lost (mean 9.73 pounds) was revealed between treatment groups. The difference between the weight loss of treatment groups and wait-list group were significant.

# Rotatori, Fox, and Switzky (1979)

Researchers followed Rotatori and Switzky's (1979) behavioral weight loss plan that spanned 19 weeks (14 weeks of treatment and 5 weeks of follow-up). Six adolescents (mean age 17.5 years) diagnosed with Down syndrome participated in the study. Participants lost a mean of 10.37 pounds during the intervention. Weight loss continued during maintenance, averaging 3.95 pounds per participant. Follow-up to

assess long-term program maintenance was conducted at 26 weeks. Three participants continued to lose weight (1.5 pounds per week) during the entire period of time.

#### Rotatori, Parrish, and Freagon (1979)

The researchers conducted a pilot study of Rotatori and Switzky's (1979) weight loss program that was implemented in a public school by a nurse. The intervention was reduced to 7 weeks with 5 weeks of maintenance and follow-up. Participants included 6 children and adolescents (aged 6 to 21 years) with mild to moderate cognitive disabilities. The nurse reviewed participants' diets and informed parents that their offspring had inadequate daily intakes of vitamins A and C, niacin, and calcium. School breakfast and lunch menus were modified to include 2% milk and whole wheat bread; while potato chips, french fries, dessert donuts, sugar-coated cereal, and second helpings were removed from participants' diets. During the 7-week treatment, a mean weight loss of 3.7 pounds was demonstrated.

# Rotatori, Fox, and Switzky (1980, part 1)

The researchers conducted a shortened 7-week behavioral weight loss study with 5-weeks maintenance, similar to their 1979 investigation. The current study was conducted with 18 adults diagnosed with mild cognitive disabilities residing in a semi-independent residential care facility. The group was divided into control and treatment groups. Participants in the treatment group lost an average of 3.60 pounds

during the intervention. A significant difference did not occur between the treatment and control groups during the maintenance period. The treatment group lost a mean of 4.4 pounds per week at the 10-week follow-up while the control group had gained 2.2 pounds.

# Rotatori, Switzky, and Fox (1980, part 2)

A study was conducted with 18 adults diagnosed with mild cognitive disabilities to evaluate the effect of a behavioral weight loss program. Participants lived in a semi-independent residential intermediate care facility. The study spanned 23 weeks: (a) 7-week behavioral weight loss intervention, with homework and monetary rewards; (b) 6-week maintenance program with monetary reward; and (c) 10-week follow-up. Participants were randomly divided and assigned to the control or treatment groups. The treatment group took part in: (a) weekly 50-minute instructional meetings teaching weight loss strategies; and (b) homework assignments, with instruction provided on completing daily weight records and food logs. Behavior therapy techniques were included (manipulation of emotional responses, elimination of food cues, changing the act of eating, use of energy to expend excess calories, and the development of activities to substitute for eating). A variety of instructional strategies were included to ensure that participants understood behavioral techniques presented: verbal explanation, modeling, videotape, simulation with feedback, and individual meetings. Participants received monetary rewards for minimal one pound weight

loss and turning in completed homework assignments.

During the behavioral intervention, the treatment group lost an average of 3.6 pounds while the control group gained an average of 1.8 pounds. Weekly meetings continued during the 6-week maintenance period. Intervention group participants were assigned to one of three monetary reward programs: (a) fixed, receiving reward at weekly meeting, if earned; (b) intermittent, receiving reward at every second meeting; and (c) intermittent, receiving reward at every third meeting. There was no significant difference in weight loss demonstrated between monetary reinforcement programs.

# Rotatori and Fox (1980)

This study replicated Rotatori and Switzky's (1979) behavior therapy weight loss program and compared it with a social nutrition for weight loss. Thirty adolescents (mean age of 18.2 years) diagnosed with moderate cognitive disabilities participated in the study that spanned 19 weeks (14 weeks of intervention and 5 weeks of maintenance). Participants were divided into three groups: (a) Rotatori-Switzky behavior therapy program; (b) social nutrition group, which met twice weekly to discuss weight loss with the school nurse; and (c) wait-list control group. Based on the results of an ANOVA, the mean weight loss produced by the behavior therapy intervention was significantly (p < .05) greater than weight lost using the social nutrition program.

The wait-list control group gained a mean of 4.42 pounds. It

appears that individuals with cognitive disabilities assigned to wait-list control groups, gain weight when told to try losing weight on their own (Rotatori & Fox, 1980; Rotatori & Switzky, 1979).

#### Fox, Rotatori, Macklin, and Green (1982)

A weight loss study for preschool children (aged 3 to 6 years old) experiencing cognitive disabilities and autism was conducted. The researchers investigated if preschooler performance was significantly different when primary reinforcers, social reinforcers, or a combination of the two were used in a standardized task-instruction format (no significant difference was demonstrated). The study is briefly mentioned to highlight the early age at which obesity may begin in children with cognitive disabilities. Education and activity as prevention and intervention measures should begin early. The participant preschoolers attended a residential facility where they were taught to be more aware of food eaten (including snacks) and cues that prompted them to eat. The intervention focused on essential components of all weight loss programs (changing nutrition habits and increasing activity). Researchers noted that parental support was vital to the success of weight loss programs for their children. Researchers also commented on the participating children's desire to lose weight; other studies reviewed did not attribute any value to self-determined choice to lose weight. Researchers also stated that positive reinforcement was a crucial element of behavior therapy weight loss programs (Stuart, 1967; Rotatori & Switzky, 1979).

Determining participant reinforcement preferences was stressed as an essential element in program planning.

### Jackson and Thorbecke (1982)

A 14-week self-control weight loss program with follow-up was conducted with 12 (11 moderate and 1 severe) overweight females between the ages of 16 and 34 years. Participants were randomly assigned to intervention and control groups. The researcher, a special education teacher, conducted separate meetings for individuals participating in the intervention and their mothers. Members of the treatment group attended 6 sessions with featured topics (such as how to eat slowly, low fat food choices, balanced meals, food portions, food groups, popular fad diets) following a review of previous topics and activities (such as dividing food cards into fattening and nonfattening categories, making balanced meals with correct food portions from all food groups, and role-play selection of one fattening item at a party). Weekly one-hour meetings were held for mothers to provide them with information on how to reduce food intake in their children.

Because the dependent weight loss variable did not consider initial weight or initial amount of excess fat, three weight loss measures were used: (a) number of kilograms lost; (b) percent of body weight lost (kilograms lost/initial weight x 100) and; (c) reduction quotient (kilograms lost/kilograms overweight x initial overweight/ideal weight x 100). Control and treatment groups were weighed at the same time of

day weekly to ensure reliability of measurement. Control group members were praised for any weight loss. Food monitoring, exercise, eating behavior, and reinforcement strategies were included in the program.

Individuals in the treatment group lost significantly more weight (4.17 kg) than those in the control group (0.42 kg). Three follow-ups were conducted. At the 29-week follow-up, the treatment group had lost 6.25 kg, in comparison with the control group weight change (-0.59 kg). The treatment group lost 9.04% of their initial weight with a reduction quotient of 50.44. The control group lost 0.50% of their weight with a reduction quotient of 2.32. The final 12-week follow-up revealed continued weight loss by the treatment group (7.33 kg) with the control group's weight remaining unchanged from the 6-month follow-up. The researchers stated that the significant weight reduction was probably strongly influenced by the monitoring and control the mothers exerted on behalf of their children.

#### Fox, Burkhart, and Rotatori (1983)

The researchers investigated the eating habits of obese and normal weight individuals with cognitive disabilities to determine if they varied. The study compared eating rate, time meal lasted, and caloric intake for 28 adults (mean age 30.3 years) with moderate cognitive disabilities (mean IQ 50.6) that worked in a sheltered workshop. Criterion used to divide the participants into two equal groups (obese and not obese) included body weight and triceps skinfolds.

Study participants were individually observed during their mealtimes on a variety of eating behavior measures (such as total clocked mealtime, number of chews and swallows, and caloric values of food intake). Researchers' conclusions confirmed the findings of similar studies on persons without disabilities; that total mealtime, caloric intake, and eating rate was not significantly different between the two groups (Bruch, 1940; Johnson, Burke, & Mayer, 1956). The finding supports evidence that obesity is largely a function of physical inactivity (Rarick, Dobbins, & Broadhead, 1976).

### Fox, Haniotes, and Rotatori (1984)

The researchers conducted an abbreviated version of the Rotatori-Switzky (1979) behavior modification program. This study consisted of a 10-week intervention with 5 weeks of maintenance and a 1-year followup. All participants worked in a sheltered workshop and lived at home with their parents. Sixteen overweight individuals (20 to 38 years of age) with moderate cognitive disabilities were randomly assigned to one of two equal number intervention groups: (a) behavioral therapy [mean age 29.5 years, mean IQs of 42.1]; and (b) behavioral therapy plus buddy reinforcement [mean age 27.5 years, mean IQs 46.3]. Peer partner dyads were formed within the plus buddy group to provide social reinforcement. Pictorial materials were included in the intervention to facilitate comprehension, practice of behavior weight loss techniques, and reinforcement. Parents were responsible for monitoring and controlling

weight loss, with the maintenance program identical for both groups.

Weight loss difference between groups was not significant at the end of the intervention (mean weight loss for therapy only group was 7.3 pounds and plus buddy group was 8.2 pounds), or after 5 weeks of maintenance (mean weight loss for therapy group only was 2.1 pounds; plus buddy group was 2.3 pounds). The one-year follow-up revealed that 37.5% (3 males and 3 females) in the sample had maintained their weight loss. The remaining study participants (62.5%) had regained to their starting weight or increased their weight. Researchers concluded that a social buddy reinforcement system with partners assigned did not enhance weight loss. Researchers stated that this finding might be attributable to a failure to establish a supportive relationship system with the partner assigned. The result might have differed if each participant had been allowed to choose their own buddy.

# Cottrell (1985)

The study reviewed replicated Cottrell and Knehans (1983) successful 7-week pilot study that produced an average 4-pound weight loss for 8 participants (aged 12 to 20 years) with moderate to severe cognitive disabilities.

Participants in Cottrell's (1985) study included 16 (10 males, 6 females) adolescents diagnosed with moderate (9) to severe (7) cognitive disabilities from an Oklahoma state run facility. Participants were divided into two groups (intervention and control) matched on age, sex,

weight, and level of MR. Participants were randomly selected from the facility's restricted-calorie list, which was the criterion used to classify obesity. The study spanned 27 weeks (7-week intervention, 8-week maintenance, and 12-week follow-up). All study participants continued facility calorie-restricted diets throughout the intervention and follow-up periods. Study measures used in analysis included height and weight, with BMIs calculated. Both groups' measurements were performed preand post-intervention, and at follow-up. Although skinfold data were obtained using techniques appropriate for children (Cachera et al., 1982), they did not correlate well with the changes in BMI and body weight and were not used during analysis.

The intervention included reinforced behavior modification with external reinforcement from researcher-trained personnel. Group 45minute weight loss technique instruction (including dietary portion control) sessions were held three times per week with weigh-ins. Any weight loss was reinforced by the research leader (verbal praise, hugs, and sugarless gum after the first week), with peers encouraged to cheer. Participants that lost weight were also given a dated *"I lost weight today"* badge, which provided nonparticipating peers and facility an opportunity to provide praise. If a participant had no weight loss or if regain occurred, verbal encouragement to do better was provided; nothing derogatory occurred.

The researcher unsuccessfully attempted to teach participants a

6-food group exchange. Eating smaller quantities of food (such as taking only one serving) rather than deprivation was emphasized during the intervention. After the treatment ended, weekly meetings ceased. During the maintenance period, participants of the intervention group continued the behavioral program on their own; weekly weigh-ins and reinforcement for weight loss continued (a meal with the diet leader in the employee cafeteria). It was ironic that the reward for weight loss was eating. Weekly weigh-ins and reinforcement did not occur after the maintenance period ended.

Results were not significant when comparisons were made between the treatment and control group. Average weight loss for the treatment group was 2.6 kilograms, and 2.39 kilograms for the control group. During the maintenance period the treatment group regained an average of 0.11 kilograms while the control group regained a mean of 0.9 kilograms. At follow-up, the treatment group's overall mean weight loss was 2.88 kilograms while the control group had lost an average of 2.64 kilograms. The researcher stressed the importance of individual food choice.

As anticipated, participants with moderate cognitive disabilities were more successful at recalling information taught than the individuals with severe cognitive impairments. Participants (4) with moderate cognitive disabilities in the treatment group lost the most weight and retained it during the maintenance period. Males in the treatment group

maintained a weight loss of over 4% at follow-up, and therefore appeared to be most responsive to the food education program. Similar changes were reflected by BMIs. The treatment group maintained their weight loss while at home during the Thanksgiving and Christmas holiday season.

# Fox, Rosenberg, and Rotatori (1985)

Researchers investigated the effects of parental involvement on weight loss for 15 participants (aged 27 to 29 years), diagnosed with moderate cognitive disabilities during a 10-week behavior therapy program. Participants were employed in a sheltered workshop and lived with their parents. Two treatment groups were formed: (a) group A, parent involved (n = 8, mean age 27 years), and (b) group B, minimal parent involvement (n = 7, mean age 29 years). Eating and activity patterns were modified to change participants' weight using behavioral therapy techniques, which included self-reinforcement. Participants from group A lost significantly more weight with less intra-group variability than group B. A strong correlation existed between level of parent involvement (measured by daily diet diary homework sheets completed and returned) and participant weight loss. At the 6-month follow-up, group A had regained an average of 3.9 pounds while group B had gained an average of 6.3 pounds. These findings support conclusions that weight loss is often short-term in individuals with cognitive disabilities and parental involvement is beneficial (Fox &

Rotatori, 1981). Weight regain has been cited as a common problem experienced by all individuals.

### Rotatori, Fox, Matson, Mehta et al. (1986)

Researchers studied the effects of a 21-week behavior therapy treatment program on 17 adolescents diagnosed with trainable cognitive disabilities. Participants were divided into three groups (one treatment and two control): behavior therapy intervention (mean age 18 years), normal-weight control (mean age 16.3 years), and wait-list control (mean age 17.2 years). Techniques used in the treatment group were: selfmonitoring, stimulus food cue elimination, exercises, and changing snack habits (included substitution of an activity). Multiple dependent measurements were performed: height, weight, triceps skinfold, abdominal circumference, and diastolic blood pressure. Participants in the two control groups gained weight while the treatment group had significant reductions to skinfold thickness, abdominal circumference, and diastolic blood pressure.

# Rotatori, Zinkgraf, Matson, and Fox (1986)

The purpose of this investigation was to determine if a maintenance program would bolster weight loss, and if so, which of two programs would work best. Participants were 13 adults diagnosed with mild to moderate cognitive disabilities. A 10-month maintenance program of weekly weigh-ins followed the 12-week behavior therapy weight loss intervention. Participants were divided into two 12-month

post-treatment groups. The experimental maintenance group (n = 7; mean age 26.2 years) had counseling booster sessions. The remaining 6 participants (mean age 35.7 years) were assigned to a weight control maintenance group. Results revealed that participants lost weight when either program was in effect. A 12-month follow-up was conducted after the maintenance programs had ended with neither group maintaining their weight loss. This might indicate that maintenance programs must be in place to be effective; they do not have lasting effects. Lifestyle change appears to be necessary to maintain weight loss.

# Norvell and Ahern (1987)

The researchers studied the effectiveness of a behavioral weight loss program conducted in the workplace. Participants were 13 obese individuals with mild to moderate cognitive disabilities that worked in a sheltered workshop. The sample was divided into control and intervention groups. After an intervention of instruction in behavior modification techniques, the treatment group lost a mean of 2.0 kilograms while the control group mean loss was 0.15 kilograms. To cross-validate their findings with similar individuals, the control group received instruction in the same behavior modification techniques after the initial study ended; they also lost weight. The pooled intervention participants lost an average of 2.7 kg. Researchers concluded that a behavior modification weight loss program could be successfully implemented to produce weight loss for individuals with cognitive

disabilities at their work place.

#### McCarran and Andrasik (1990)

The researchers conducted a 14-week weight loss intervention for 8 adults with dual diagnosis of mild to borderline cognitive disabilities and cerebral palsy to determine if caretaker or parental involvement aided weight loss. Participants were divided into two groups: (a) group A, home-help; and (b) group B, no help. Researchers stated that the weight loss difference between groups was clinically, but not statistically, significant. The finding suggested that sufficient power to produce statistical significance might be provided with a larger sample. Group A participants lost 5.5 pounds while group B lost 2.7 pounds. At the 1-year follow-up, group A maintained a mean weight loss of 3.4 pounds and group B regained an average of 1.1 pounds. The researchers concluded that parental/caretaker participation did not produce significant weight loss. Generalizability of results to individuals with cognitive disabilities could be limited because IQs of 3 participants were 78 or above. Schloss and Alper (1997)

The purpose of this study was to determine if individuals with cognitive disabilities living in a group home could be taught to plan and shop for 3-days worth of nutritionally sound meals and inventory their food supplies. Participants were 3 male adolescents (aged 16 to 17 years) attending public school, and dually diagnosed with cognitive disabilities and mental illness that considered fitness and ability levels. Researchers

conducted a 5-week study with 60-day follow-up. Anthropometric measures, including weight, were not pertinent to this study.

The study was based on a 4-food group program using daily totals of recommended dietary allowances (RDA) of vitamins and minerals from manufacturer labels as the criteria for measuring meal healthfulness. Caloric content of meals was also tracked. Authors noted that the high participant interest displayed during the study could have been associated with grocery shopping trips. The study design followed an applied behavior, single-subject, multiple probe design across individuals, with 5-day baseline. Results indicated that individual caloric intake was relatively stable across the baseline, intervention, and follow-up. Similar RDA percentage ranges were demonstrated in the data tracked by facility staff. This finding might indicate that participants ate the same foods habitually, with little meal variety. At the 60-day followup, participants continued to maintain meal plans at 100% RDA and daily total calories were within the recommended range for gender and age. The structured nature of the program might partially account for this finding.

Schloss and Alper (1997) concluded that including this type instruction in school transition programs might provide nutrition training needed by individuals with cognitive disabilities. Researchers suggested that the program content be modified to include meal variety (different foods), authentic grocery shopping experiences with individuals

paying for their purchases, and health education (wise food choices and caloric intake). Researchers stated that unexpected difficulties were encountered when planning and implementing this program, even though they were special educators. Initial materials were not appropriate for the abilities and needs of participants with cognitive disabilities. Poor fine motor skills required that larger squares be used for meal planning charts. A different system for recording meal selections was necessary because of participants' poor writing and spelling abilities. Reading skill deficits required that pictures be used and a limited sight word vocabulary developed during this study. The need for research into nutrition training for this population was stressed with ability level and disability category considered.

# Summary of Behavioral Weight Loss Studies

Twenty-eight behavior modification weight loss studies were reviewed that met with varying degrees of success. The mean number of individual study participants was 11.96 (range between 1 and 32), was tri-modal (1, 3, 18), and had a median of 12. Only four studies (14.81%) included 21 or more participants. Participants ranged in age from 3 to 48. Criterion used to define participants as overweight or obese was not provided in 17 studies (60.71%). Six (22.2%) studies used a specific percentage over ideal or desired weight on standardized charts and tables as the basis to designate participants having excess weight. Five studies (18.51%) included participants that had been identified as having weight

problems by dietary staff, researchers, or that made unsuccessful progress on doctor supervised calorie restricted diets. None of the studies indicated participants had self-identified a desire to lose weight, which has been deemed necessary to successfully maintain weight loss (Fox, Rotatori, Macklin, & Green, 1982).

Weight was the primary dependent variable in 25 (92.59%) of the behavior modification studies. Only three studies (11%) involved measures in addition to height and weight (Cottrell, 1985; Fox, Burkhart, & Rotatori, 1983; Rotatori, Fox, Matson et al., 1986). Research study settings and participants' living arrangements varied: (a) 9 studies (33.3%) included participants from institutional or residential care facilities; (b) 6 studies (22.22%) included sheltered workshops, daycare-training facilities, and group homes; and (c) 5 studies (18.51%) included a public school setting. Mean length of behavioral intervention was 14.08 weeks (ranging from 5 to 38 weeks); mode was 14 with a median of 13 weeks. Two studies contained a plan (4.3 and 15 weeks) to fade reinforcement for successfully following weight loss interventions (Foxx, 1972; Moore & Crum, 1969). A maintenance plan following the intervention was included in 9 studies (33.3%) (mean was 6 weeks, range 5 to 10 weeks, mode and median was 5 weeks). Follow-up of study participants varied: (a) 8 studies (29.62%) had no follow-up; (b) 14 studies [51.85%) had a follow-up plan lasting between 4 weeks and 9 months; and (c) only 5 studies (18.51%) included a long-term follow-up

as long as one year (Altman, Bondy, & Hirsch, 1978; Fox, Haniotes, & Rotatori, 1984; Jackson & Thorbecke, 1982; McCarran & Andrasik, 1990; Rotatori, Zinkgraf, Matson, & Fox, 1986).

Weight loss is a complex interaction of biological and psychological factors, and strict adherence to interventions (behavioral treatments, calorie restriction, exercise, fad diets, medication, surgical, and psychotherapy) that may be of limited long-term value without lifestyle change (Wooley & Garner, 1994). The sole cause of obesity is rarely a medical or physical disorder, although these factors might influence the propensity to become obese and effect treatment (Rotatori, Switzky, & Fox, 1983). Five studies (18.51%) reviewed mentioned clinical conditions in some or all participants: Prader-Willi syndrome [2], Down syndrome [1], cerebral palsy [1], and orthopedic impairment [1]. Two (7%) of the studies did not include weight outcomes (Jackson & Thorbecke, 1982; Schloss & Alper, 1997). The eating habits of obese and non-obese individuals with cognitive disabilities did not vary significantly between groups in one study (Jackson & Thorbecke); it is likely that snacking and level of activity might partially explain weight difference. Results of the Schloss and Alper study supported the position that individuals with cognitive disabilities could learn to use food labels (with assistance) to plan and shop for meals that followed RDA and caloric guidelines.

Elimination of eating stimulus cues by avoidance or activity substitution was a behavior therapy technique used in many of the

studies. Seven (25.9%) of the studies involved some type of education related to nutrition or exercise to expend calories. Two school studies encouraged exercise, without having a program (Buford, 1975; Foreyt & Parks, 1975; Fox, Haniotes, & Rotatori, 1984; Gumaer & Simon, 1977; Jackson & Thorbecke, 1982; Rotatori, Fox, Matson, et al., 1986; Schloss & Alper, 1997). Eight studies (29.62%) noted the involvement of parents or caretaker (McCarran & Andrasik, 1990). Two stated that a strong correlation was found between parental involvement and weight loss (Fox, Rosenberg, & Rotatori, 1985; Jackson & Thorbecke, 1982). McCarran and Andrasik (1990) stated that assistance did not aid in weight loss of persons with cerebral palsy (3 persons had IQs exceeding 78). Fox, Haniotes, and Rotatori (1984) conducted an unsuccessful study that explored the viability of using assigned buddies to stimulate weight loss. Although findings of the study were not significant, the general population successfully practices the strategy of working with a chosen partner frequently in exercise programs.

# Limitations of Behavior Weight Loss Studies

Small sample size is a problem inherent to the study of this population. Limited use of control groups 37% (10 of 27 studies) hampers reliability and validity of results. Failure to provide sufficient detail about interventions limits replication. Insufficient description of participants limits generalizability of results. Poor long-term follow-up on weight loss retention was a weakness (generalizability, reliability, and

validity) of many studies reviewed. Researchers concluded that longterm reinforcement alone might be insufficient for maintenance of weight loss (Foxx, 1972). Diet alone was stated as an unsuccessful weight loss strategy in 5 (18.51%) studies (Foxx; Harmatz & Lapuc, 1969; Moore & Crum, 1969; Rotatori, Parrish, & Freagon, 1979; Upper & Newton, 1971). A few interventions were too complicated (food exchange system) for individuals with cognitive disabilities to adhere to alone. These employed cumbersome or time consuming techniques (multiple daily or weekly weigh-ins and food logs), or initial materials and concepts that were not appropriate for participants (Cottrell, 1985; Joachim, 1977; Schloss & Alper, 1997).

In order for weight to be controlled (lost or maintained) in this population, a system of continued support is needed (Altman, Bondy, & Hirsch, 1978). The viability of post follow-up maintenance-support plans proved successful after 1 year (Rotatori, Zinkgraf et al., 1986). Seventeen (60.7%) studies included strategies that would be difficult to continue (such as counseling, tokens, and monetary or other reinforcement programs). Reinforcement of targeted behaviors in studies included artificial systems hard to replicate outside controlled settings. Lack of generalization strategies from a controlled setting into a community environment might be a partial cause for long-term program failures. Individual weight loss programs should be desired, easy to understand, and simple to follow (Joachim, 1977; Schloss & Alper, 1997). In practical

terms, measures used among studies were different and required researcher conversion for comparisons (inches-centimeters, poundskilograms, days-weeks-months). Criterion differed among studies (weight level, obesity category, cognitive impairment, developmental age, and length of time required to signify successful weight loss). Review of intervention studies demonstrated that individuals with disabilities have eating styles and personality characteristics similar to their nondisabled peers (Burkhart, Fox, & Rotatori, 1985). Lifestyle changes are needed that include nutrition and activity.

## Conclusions from Behavioral Studies

Behavioral weight loss programs have shown mixed results with limited long-term success. Program attrition, maintenance of weight loss, and continuation of monitoring or reinforcement were problems cited in studies (Gould, Feltz, Horn, & Weiss, 1982, 1985). Certain behavior modification strategies (such as self-monitoring, and identification and elimination of eating cues) are required to important to achieving and maintain healthy weight status. Increased self-awareness was seen as a form of self-monitoring and motivation for participants. Research stated a need existed to identify reinforcement preferences when planning a program of intervention and that might include reinforcements that could be continued after an intervention ended (Fox, Rotatori, Macklin, Green, 1983). Developing a support system (such as therapists, teachers, and facility personnel) proved an effective strategy

for weight loss. Social and parental support was demonstrated as successful.

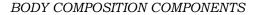
## Health-Related Fitness

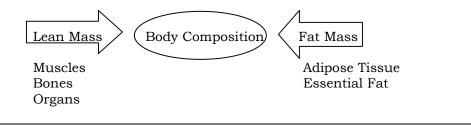
A combination of increased activity and nutritious eating has long been known to promote health and affect weight (Insel & Roth, 2004; Niesworth & Smith, 1978). The activities of life (such as work and recreation) are more easily managed when body strength is increased in response to activity (Lieberman, 2002; Price, 1980). Health-related fitness is focused on how well the body feels and acts, and current health education uses the energy balance equation as the basis for overall wellness (Insel & Roth, 2004). Quality of life, including attitude, is greatly influenced by the components of health-related fitness (body composition, muscle strength, muscle endurance, cardiovascular strength, and flexibility) (Insel & Roth, 2004, Sherrill, 1998a, 1998b). Body composition is considered a good indication of overall wellness and is linked to many chronic illnesses (including obesity) (NIH, 1996; CDC 2000, 2004; Greenwood, 1983).

# Overview of Body Composition

The human body is composed of lean mass (muscle, bone, and organs) and fat mass (adipose tissue) (Figure 3). Fluid levels have a temporary effect on body composition. Body size or mass (weight) is the sum total of the body's components. Body composition is influenced by the proportion of lean mass to fat mass, including its distribution.

### Figure 3





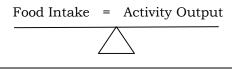
*Note: The body is composed of lean and fat mass.* 

Muscles are dense and composed of less air than fat. To illustrate the difference, a pound of meat uses less space than a pound of ice-cream, which is composed of more air. The body can be made to look and act differently by how taunt (toned) the muscles are and how well they work in concert with the bones. An individual can actually weigh more, yet look smaller, when the body is composed of more lean mass than fat mass. Adults 20 and older are considered overweight with body fat estimates  $\geq$  25%, and obese at  $\geq$  30% (CDC 2000, 2004; Dietz, 1987; USDHHS, 1996).

The energy balance equation (Figure 4) is currently used to explain the healthy maintenance of body weight as daily food intake equal to calories expended (Insel & Roth, 2004). Food intake is measured in kilocalories (referred to as calories), with variation in the quantity and type calories contained in different foods. Calories are converted to energy that is burned by body system processes necessary to sustain life, daily activities, and moderate to vigorous exercise (Insel & Roth). Excess

### Figure 4

#### ENERGY BALANCE EQUATION



*Note:* Weight maintenance requires that daily calories from food intake and energy <u>expended are the same.</u> Weight gain occurs when food intake exceeds calories expended.

energy (calories) is stored as adipose tissue (fat). Five weight status classifications (underweight through extremely [morbidly] obese) currently exist and designate levels of fatness that have been associated with risks for developing chronic illness (Table 11) (CDC, 2000, 2004). Weight levels were established through research and normed on individuals without disabilities (Foreyt & Parks, 1975; Foxx, 1972; Gibson, 1997; Jackson & Thorbecke, 1982; McCarran & Andrasik, 1990; Nordgren, 1970; Upper & Newton, 1972). A need to establish guidelines for individuals with disabilities based on percentage of body fat exists (Pitetti, Rimmer, & Fernhall, 1993).

Reviews of literature to determine the effects of exercise training on the components of health-related fitness for individuals with cognitive disabilities suggest that: (a) cardiovascular and muscular endurance are positively influenced by programs of long duration, (b) resistance exercise strengthens muscles, and (c) high frequency programs increase flexibility (Chanias et al., 1998; Pitetti, Rimmer & Fernhall, 1993). The least

Level of Weight Status and Risk o Children (2-20) and Adults (Over 20)	Status and Adults (Ove	d Risk of Disease er 20)	ase			
Weight Status (Fatness)	Obesity Class	Children's BMI Range Percentile	Adult BMI (kg/m²)	Risk of Obesity- Associated Discase	Combined BMI & W M ≤ 40° (102 cm) F ≤ 35° (88 cm)	Combined BMI & Waist Circumference M ≤ 40" (102 cm) ≥ 40" (102 cm) F ≤ 35" ( 88 cm) ≥ 35" ( 88 cm)
Underweight			Below 18.5%	F		
Normal			18.5% 24.9%	,		
Overweight		85 to 95	25.0% - 29.9%	High	Increased	High
Obesity	<b>1</b>	2 95	30.0% 34.9%	Very High	High	Very High
	II		35.0% 39.9%	Very High	Very High	Very High
Extreme Obesity (Morbid Obesity)	Ш		40.0% & above	Extremely High	Extremely High	Extremely High
Note: BMI is correlated with body fat and as it osteoarthritis, some cancers, and diabetes). At th women may have more body fat than men and, ( plotted as percentiles on age and gender specific obesity-associated chronic disease include: diet, history of disease. Sources: Calle et al. (1999): World Health Organization (1995).	ed with body fincers, and diab recers, and diab reducers fram nage and gene nage and gene reces: Calle et at tion (1995).	at and as it increase etes). At the same men and, (2) older der specific growth chude: diet, physica al. (1999): CDC (2)	ss, the risk for some condi height, two people can ha people may have more bo charts. BMI alone is not charts. BMI alone is not activity level, waist circu 004); Gallagher et al. (199	Note: BMI is correlated with body fat and as it increases, the risk for some conditions increases (premature death, cardiovascular disease, high blood pressure, osteoarthritis, some cancers, and diabetes). At the same bMI (1) women may have more body fat than younger adults. BMI for children and teens (age 2 to 20 years) are plotted as percentiles on age and gender specific growth charts. BMI alone is not a diagnostic tool, other health factors to consider when assessing risk of obesity-associated chronic disease include: diet, physical activity level, waist circumference, blood pressure, blood sugar level, cholesterol level, and family history of disease. Sources: Calle et al. (1999): CDC (2004); Gallagher et al. (1996); Garrow & Webster (1985); National Heart Lung Blood Institute (1998); World Health Organization (1995).	death, cardiovascular disea rrent body fat percentage. BMI for children and teet Ith factors to consider when blood sugar level, cholestet 85); National Heart Lung B	ise, high blood pressure, At the same BMI (1) as (age 2 to 20 years) are a assessing risk of arol level, and family 3lood Institute (1998);

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Table 11:

researched areas of health-related fitness in individuals with disabilities are body composition, flexibility, and muscular strength (Chanias et al.). Research has been conducted on the effects of exercise on body composition and obesity in the general population with little focus on individuals with cognitive disabilities (Burkett & Phillips, 1994; Millar, Fernhall & Burkett, 1993). It has been theorized that the lack of research into body composition for this population is associated with lack of proven skinfold formulas and appropriate measurement devices (Burkett & Phillips, 1994; Kelly & Rimmer, 1987; Kelly, Rimmer, & Ness, 1986).

Conclusions drawn from research conducted with individuals having cognitive or physical disabilities, indicated a tendency to be inactive, sometimes due to movement problems (Beasley, 1982; Campbell, 1973; Coleman & Whitman, 1984; Dresen, DeGroot, Mesa Menor, & Bauman, 1985; Fox & Rotatori, 1982). Sedentary lifestyle is characterized by low level of activity, which is hypothesized as the reason for the high prevalence of obesity and low level of cardiovascular fitness in individuals with cognitive disabilities (Fernhall, Tymeson, & Webster, 1988; Millar, Fernhall, & Burkett, 1993).

Health-related fitness views body size more closely through its composition than weight, which is affected by both adiposity and muscle tissue with obesity reflected as the percentage of fat the body contains. When researchers began to develop interventions for obese persons with

cognitive disabilities, the early studies focused on the effect of controlling eating (patterns and quantities) without increasing activity. Ultimately, it appears that techniques effective in maintaining or changing the body composition of persons without disabilities are the same strategies needed for persons with cognitive impairments. Few studies have been conducted with individuals having cognitive disabilities that combine nutrition and exercise to improve health-related fitness. Lack of followup was a weakness present in many behavioral weight loss studies with persons experiencing cognitive disabilities.

## Motor Skill Development and Cognitive Disabilities

When increased activity was recognized as a possible strategy to remediate obesity in the general population, the motor skill abilities and physical fitness of individuals with cognitive disabilities had to be considered prior to inclusion in interventions (Rarick, Dobbins, & Broadhead, 1976; Rotatori, Fox, Litton, & Wade, 1985). Physical fitness appears to work in concert with motor skills to build health and enhance quality of life. There are two types of motor skills: fine (used in manual dexterity activities such as writing and picking up coins), and gross (large muscle movement activities such as running).

The disparity in motor skill acquisition and physical fitness of individuals experiencing cognitive impairments were recognized by early researchers (Francis & Rarick, 1959; Rarick & McKee, 1949). Initial motor skill research for children with cognitive disabilities emerged from

the early childhood developmental discipline and appeared to be directed toward establishing normative scales or fundamental performance standards (Haring & Sawey, 1984; Rarick & McKee). Motor skill related activities (agility, balance, coordination, speed, power, and reaction time) were variables targeted in representative studies reviewed, rather than health outcomes. Attributes of physical fitness related to health and activities of life (body composition, aerobic cardiorespiratory endurance, flexibility, muscular strength and muscular endurance) were infrequently of interest (Cooper, 1982; Cooper Institute for Aerobics Research, 1994a, 1994b; Sherrill, 1998a, 1998b).

Researchers again focused their attention on the historic lag of fine and gross motor development between persons with and without cognitive disabilities when exercise and physical education programs were developed (Auxter, 1961; Cratty, 1967; Denny, 1964; Drowatzky, 1971; Francis & Rarick, 1959; Howe, 1959; Lipman, 1963; Malpass, 1963; Rarick & Dobbins, 1972; Rarick & McKee, 1949; Rarick, Widdop & Broadhead, 1970; Sengstock, 1966; Stevens & Heber, 1964). The physical fitness profiles of children though young adults with developmental disabilities (such as mild to moderate MR, Down syndrome, autism, multiple disabilities) studied were lower than their peers without disabilities, resulting in a misconception that these individuals were unable to participate in traditional physical education programs (Campbell, 1973; Coleman, Ayoub, & Fredrick, 1976a; Maksud

& Hamilton, 1999; Shannon, 1985; Sharp, Pitetti, Rogers, Bohlken, & Abendroth, 2002; Winnick & Short, 1999). Testing procedures varied markedly between investigations reviewed, however, the results were in general agreement and supported the hypothesis that motor and physical performance could be enhanced through planned programs of training and instruction in motor skills (Chanias et al., 1998; Pitetti, Rimmer, & Fernhall, 1993).

# Brief Review of Motor Development Studies

A brief overview of four early motor development studies on individuals with cognitive disabilities is included in Table 12 to provide historic perspective.

*Francis and Rarick (1959).* Their study included 284 children diagnosed with educable cognitive disabilities attending special education classes in Madison and Milwaukee, Wisconsin public schools. A battery of gross motor skills (such as strength, power, speed, balance, and flexibility) was targeted, with skill trends by gender and age examined. Findings indicated that intelligence, as measured by standardized tests, was positively correlated with most of the motor performance tasks. When mean scores were compared to published norms for children without disabilities, a lag of two to four years was seen in children with cognitive disabilities; developmental patterns followed approximately the same trends for gender and age. The discrepancy gap between groups of children tended to increase as they

Motor Skill Development in Individuals with Cognitive Disabilities	ndividuals with Cognitive L	hsabilities	
Year & Study	N, Sex	Measures	Findings
1959 - Francis and Rarick	284 children, public school	Selected gross motor skills Comparison	<ol> <li>Similar skill developmental sequence</li> <li>2 to 4 year gap in published norms on children without disabilities</li> <li>Greater variance increased with age and complexity of skill</li> <li>Skill performance correlated with IQ</li> </ol>
1959 - Howe	86 children (43 with, 43 without MR, matched by age)	Selected motor skills	Skills were practiced prior to assessment; verbal reinforcement used during assessment; performance of children without disabilities was consistently superior on all tasks
1970 - Rarick, Widdop, & Broadhead	4,325 national sample of children with MR	Modified AAHPER youth fitness test	2 to 4 year gap between published norms for children without disabilities
1972 - Rarick & Dobbins	children with MR	Selected gross motor skills Comparison	Selected Confirmed Francis & Rarick study results gross motor Children with cognitive disabilities lagged behind skills children without disabilities on measures of health- Comparison related fitness (flexibility, muscular strength and endurance), balance and agility).

Table 12

aged, with greater variance displayed in development of complex skills. Rarick and Dobbins (1972) confirmed findings that children with cognitive disabilities lagged behind children without disabilities on measures of health related fitness (flexibility, muscular strength and endurance, balance and agility).

*Howe (1959).* The relationship between intelligence test scores and performance results on selected motor tasks (standing high jump, accuracy of thrown ball, balance, grip strength, fifty-yard dash, dodging run, and squat thrust) was explored among 86 public school children (43 with disabilities, 43 without) matched by chronological age. Children practiced demonstrated skills until expectations were understood. Verbal reinforcement was used during assessment. Howe concluded that the performance of children without disabilities was consistently superior on all tasks.

*Rarick, Widdop, and Broadhead (1970).* The researchers attempted to develop national motor performance skill standards and goals for children with cognitive disabilities (Copeland & Hughes, 2002). The researchers rationalized that appropriate norms for this population might motivate schools to improve physical fitness programs (motor skill goals, development, and maintenance) and provide reasonable levels of physical fitness for all children. The motor performance of a national sample of 4,325 children with cognitive disabilities on a modified version of the AAHPER Youth Fitness Test (1968) for both genders at all age levels, was

compared to national standards established for children without cognitive disabilities in this study. Supportive of earlier findings, results indicated that a substantial performance delay (two to four years) existed for children with cognitive disabilities on all tests when compared to children without disabilities (Francis and Rarick, 1959).

# Summary of Motor Skill Development

Early research established that the motor development sequence was similar in all children (Francis and Rarick, 1959). A two to four year developmental lag in fine and gross motor skills was recognized in children having cognitive disabilities that broadened with age and skill complexity, often leading to a lower level of over all motor skill attainment (Cratty, 1967, 1962; Denny, 1964; Drowatzky, 1971; Francis & Rarick; Gillespie, 2003; Howe, 1959; Lipman, 1963; Malpass, 1963; Rarick & Dobbins, 1972; Rarick, Widdop, & Broadhead, 1970; Rimmer, 1999; Sengstock, 1966; Stevens & Heber, 1964). The lag in motor skill development for children with cognitive disabilities has been recognized for almost 50 years. When physical fitness and health education practices, methods, programs, materials, and opportunities for persons with cognitive disabilities are considered, a similar lag is also seen.

## Physical Fitness Awareness

The Sharp et al. (2002) study with students displaying cognitive disabilities indicated that their health-related physical performance could be enhanced through regular physical activity. Outside factors (such as

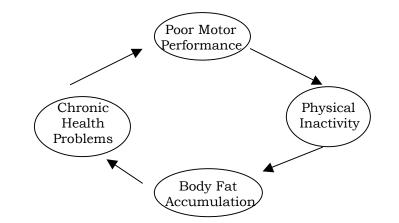
the attitudes of persons without disabilities and the stigma of lowered expectations and opportunities attached to disability) have a great effect on participation in community activities and health clubs (Baer & Wolfe, 1970; MacMillan & Meyers, 1979; MacMillian et al., 1997; Mesibov, Adams, & Klinger, 1997; Rimmer, 1994; Siperstein et al., 2003; Turnbull et al., 2004). It has been estimated that 60% of Americans are not physically active, and only 12% of the 54 million Americans with significant disabilities engage in moderate activity (USDHHS, 1996). In 2003, Draheim, Williams, and McCubbin reviewed the community physical activity habits of 152 (76 males [mean age 35] and 76 females [mean age 38]) with cognitive disabilities assessed in the NHANES II and Physical Activity Survey. Results indicated that individuals of both gender participated equally in leisure physical activities, 49% took part in little activity, and 13% participated in some activity. Walking and cycling were the activities most participated in by persons with cognitive disabilities.

The movement to become physically fit was promoted by the U.S. government, prompting research into factors contributing to fitness. The characteristics of 20 third-grade children without disabilities, which exhibited extremely high levels of motor proficiency, were explored, with height identified as a contributing factor (Rarick & McKee, 1949). Height and its relationship to physical fitness and health then became an area of interest (Dutton, 1959; Kugel & Mohr, 1963; Pozsonji & Lobb, 1967;

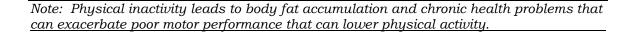
Rarick, Dobbins, & Broadhead, 1976). Institutionalized children with cognitive disabilities were found to be shorter than children without, leading to theories that shortness become greater as level of cognitive impairment increased (Kugel & Mohr). Evidence supported findings that individuals with certain chromosomal, congenital anomalies, and metabolic deficiencies might be shorter in stature (Dutton; Pozsonji & Lobb). Metabolic deficiencies were not indicated in children with cognitive disabilities as a class (Rarick, Dobbins, & Broadhead).

Francis and Rarick (1959) found the heights and weights of individuals with disabilities to be within normal limits, with a tendency to be heavy for height. Excess weight trended upward with increasing age (Rarick, Dobbins, & Broadhead, 1976). Skinfold thicknesses and relative weights of children with cognitive disabilities were significantly greater than their nondisabled peers. Research studies support these findings. Studies have indicated that dietary habits were similar in persons with and without obesity, and body composition was more closely linked to physical activity than caloric intake (Bruch, 1940; Fox, Burkhart, & Rotatori, 1983; Johnson, Burke, & Mayer, 1956; Parizkova, 1963, 1966; Parizkova & Stankova, 1967). Excess body fat and low motor proficiency are indications of limited participation in physical activity. The excess body fat, chronic health problems, inactivity, and poor motor performance demonstrated by individuals with cognitive disabilities suggests the existence (Figure 5) of a perpetuating

### Figure 5



#### CYCLE OF OVERWEIGHT AND OBESITY IN PERSONS WITH DISABILITIES



inter-related cycle (Rarick, Dobbins, & Broadhead). A great percentage of individuals with cognitive and physical disabilities have been found to be very inactive, resulting in overweight and obesity (Beasley, 1982; Campbell, Bauman, 1985; Coleman & Whitman, 1984; Dresen, DeGroot, Mesa Menor, & Bauman, 1985; Fernhall, Tymeson, & Webster, 1988; Fox & Rotatori, 1982; Litchford, 1987; Millar, Fernhall, & Burke, 1993; Rarick, Dobbins, & Broadhead, 1973).

The cohort conducted by Wier, Ayers, Jackson, Rossum, Poston, and Foreyt (2001) with 496 NASA employees, concluded that habitual physical activity is a significant source of long-term weight change for weight control. Lifestyle change is considered a strategy to lose weight with 6 months considered a good timeframe for losing 10 pounds (CDC, 2004). It would appear this same move to become and remain physically active could result in health and weight management benefits for persons with cognitive disabilities.

### Physical Education

The historic need for a program of fitness that positively impacts health (such as physical fitness and weight maintenance) in persons with disabilities continues to be apparent (Auxter, 1961; Auxter & Pyfer, 1985, 1989; USDHHS, 1996). The review of literature associated with health-related physical fitness for this population, branched into areas involving work, recreation and leisure activities, and needed social skills that must ultimately be addressed in IEP goals (Denny, 1964; Deno & Mirkin, 1980; Fain, 1986; Modell & Valdez, 2002; Vandercook, 1991; Wehman, 1978).

Physical education programs became more concerned with overall fitness in the mid-60s in response to concern over the 1953 Kraus-Weber report findings that American children were less fit than peers in Europe. Presidential fitness initiatives began stressing public awareness of physical fitness in 1956, (President's Council on Physical Fitness, 2004; Rarick, 1980). The first President's Challenge and pilot national testing program took place in 1957, with 8,500 boys and girls aged 5 to 12, with national time samples taken between 1953 and 1975, indicating continued decreased physical performance.

The Presidential Sports Awards were established in 1972 to

motivate American children to participate regularly in fitness and sports activities; 49 categories of awards were available in 1975. Continued emphasis on physical fitness and exercise became evident when it became one of the 15 priority areas in the 1977 National Health Promotion Disease Prevention Initiative. The Amateur Sports Act of 1978 was passed and the USOC reorganized. The National School Population Fitness Survey, began in 1985, initiated a National Physical Fitness award for school fitness programs. Presidents began this emphasis on fitness under Eisenhower, and it has grown under succeeding presidents. Activities such as the *American Workouts* on the White House lawn were followed by fitness chairman Schwarzenegger's visits to advocate for daily, quality physical exercise in all 50 states. The 1996 landmark *Physical Activity and Health: A Report by the Surgeon General* spurred the *Healthy People* goals for 2000 (1991) and 2010 (2000).

# PE and Individuals with Cognitive Disabilities

The fitness needs, of individuals with cognitive disabilities, initially recognized were muscular strength and endurance required for manual labor positions (Beasley, 1982; Nordgren & Backstrom, 1971). Their health needs were neither acknowledged nor emphasized until the *GAP Report* (Appendix C) was issued by the U.S. Surgeon General in 2000. The late 1970s saw an increase in research focused on the ability of individuals with severe disabilities to use recreational equipment, acquire leisure skills, and generalize them to authentic community environments

with persons not having disabilities (Wehman, 1978; Wehman & Marchant, 1977). Research into total health-related fitness for this population has been slow to follow.

The passage of Public Law 94-142 in 1975 (renamed Individuals with Disabilities Education Act [IDEA]), and its subsequent amendments, mandated that physical education was made available to all children with disabilities as part of their free appropriate public education in the least restrictive environment (U.S. Department of Education [USDE], 1997, 2000, 2001, 2002, 2003; U.S. Department of Health, Education, and Welfare [USDHEW], 1979). The legislation prompted professional development and research focused, objective-based instruction, adaptive physical education programs, behavior modification, and integration techniques (Kelly, 1965; Rynders, Johnson, & Johnson, 1980; Winnick, 1984). An increased trend toward inclusion in general education classes and increased parental participation in the IEP process was mandated in 1986 (Public Law 99-457).

IDEA '97 placed an emphasis on including individuals with disabilities in the community and called for instruction to occur in those settings (Flexer, Simmons, Luft, & Baer, 2001; Funk, 1992; SRI International, 1993). This directive placed a necessary emphasis on skills appropriate for entry into the community. Sports and recreational environments are the most realistic, authentic venues for inclusion, and opportunities for social interaction and cooperative learning (Krebs &

Block, 1992; Modell & Valdez, 2002; Passer, 1982; Rynders, Johnson & Johnson, 1980; Shores, 1987).

## Adaptive Physical Education

Adaptive physical education (APE) was designed to: (a) address the unique psychomotor needs of children with special needs through remediation and reinforcement; and (b) facilitate self-actualization [realizing all of one's psychomotor potentials] that fosters enjoyment and thereby forms active participation habits in sports, dance, and aquatics (Sherrill, 1998a, 1998b). Rather than follow the 1970s and 1980s medically-based movement model that often focused on segregated physical therapy and rehabilitation in isolation (Duke & Sherrill, 1980; Folio & Norman, 1981; Peterson & Guinn, 1984), this educationallybased approach to physical activity utilized a curriculum that integrated behavior domains and the joy of purposeful movement. Behavior domains include: (a) cognitive [intellectual skills for perceptual-motor functions]; (b) affective [emotions, attitudes, values, interests, and desires]; (c) intentions [displayed as body image, self-concept, social competency, inclusion, fun and mental health]; and (d) psychomotor [sensorimotor functions, physical fitness, and motor fitness, motor skills and patterns] (Sherrill, 1998a, 1998b).

It is important to note that *adaptive* is included in the legal definition of MR and is an adjective that describes behaviors, skills, and functions that should not be confused with adapting, a verb that implies

modification. The controversial term *disability* is often defined in adaptive physical education circles as reduction or loss of functional ability and/or activity (Sherrill, 1998b; WHO, 1980). Physical education and fitness for students without disabilities has been part of the mainstream curriculum for nearly 100 years (Seamon, 2001; Sherrill, 1998a, 1998b). The social minority, or individual difference, model of physical education was recommended in the 1990s for individuals with disabilities (Sherrill, 1998a, 1998b). There were a variety of disability sports events and adaptations devised to motivate children with cognitive and physical differences to become community athletic participants (Shapiro, 2003). The current education model to develop, improve, and maintain fitness includes large and small muscles in moderate daily activities, and the fun of sports and exercise not accounted for in rehabilitation programs (Funk, 2001; Ljungkvist, 2000; Seamon, 2001).

Adaptive physical education researchers have explained the unpurposeful movement of persons with disabilities as *amotivation*, which they linked to learned-helplessness (low persistence at challenges and a perception of external control) (Martinek & Griffith, 1994; Siegel, 1979; Reid, Montgomery, & Seidl, 1985, 1989; Reid, Vallerand, & Poulin, 2001). A primary purpose of adaptive physical education is to teach motor skills (Table 13) that contribute to independent living, beginning with purposeful movement (sensorimotor input and processing), progressing to demonstrated abilities, and advancing to learned skills

Table 13

Functional			
Level	Description	Examples	
Basic Cognitive	<u>Reflexes</u> Equilibrium Primitive Sensorimotor input Processing	<u>Systems</u> Audition Kinesthetic Tactile Vestibular	<u>Vision</u> Orthoptic Refractive
Abilities	<u>Perceptual–motor</u> Balance Spatial Awareness Directionality Cross-lateral integration Laterality Body Image	<u>Physical fitness</u> Strength Flexibility Muscular endurance Cardiovascular endurance Body composition	<u>Motor fitness</u> Power Agility Motor coordination
Skills	<u>Functional skills</u> Walking Running Sitting Climbing	<u>Sports skills</u> Swimming Throwing bocce ball Rolling a bowling ball Shooting a basketball Batting a ball	

MOTOR LEARNING LEVELS WITH EXAMPLES

Physical Education and Recreation (5th, 6th), p. 41, 42.

needed for the general tasks of daily living, activity, and recreation

(Auxter & Pyfer, 1985).

Behavior Therapy Techniques for Motor Skills

Behavior therapy techniques initially used to manage undesirable behavior in this population, then explored as weight loss strategies (Stuart, 1967; Abramson, 1967; Wollersheim, 1970), were investigated as methods for learning motor and physical skills. Strategies to analyze the results of behavior therapy, known as applied behavior analysis (ABA), were especially useful to special educators and researchers for assessment because they emphasized the use of systematic observation techniques to specify entry and terminal behaviors appropriate for groups or individuals.

ABA strategies were incorporated into physical education and adaptive physical education classes because they provided precise, welldefined, individualized instructional outcome goals that were observable, and could be measured following reinforced intervention (such as task analysis and shaping procedures) (Loovis, 1980). The exploration of contingent reinforcement strategies, used singularly or in combination with other variables, on the learning and performance of motor tasks that might affect body composition and physical fitness in persons with cognitive disabilities is of particular interest to this study.

## Behavior Therapy Motor Skill Studies

Brief reviews of five studies provided a historic perspective of research conducted using behavior modification techniques to teach motor and physical skills (Table 14).

*Wagoner (1968).* The effect of three reinforcement conditions on repeated trials of physical proficiency for females was investigated. Three participant groups were formed (one with cognitive disabilities and two without), matched on chronological and mental ages. Treatment conditions consisted of standard instructional methods, active encouragement, and candy reward. The dependent measures were grip strength, standing broad jump, 30-yard dash, and volleyball throw

Year & Researcher	N, Sex	How	Dependent Measures	Reinforcement Treatments	Performance Results
1968 - Wagoner	Females; 3 groups; (1 MR, 2 ND)	Repeated trials	Grip strength, distance ball throw, standing broad jump, 30-yd dash	Effect 3 reinforcements on motor skill proficiency: Standard instruction, active encouragement, token candy reward	All groups better with active encouragement added to standard instruction
1969 - Solomon	81 males (age Repeated 14-17); 3 groups trials (10) (2 MR, 1 ND); on 5 DVs Public schools & institutions	Repeated trials (10) on 5 DVs	Standing broad jump, shuttle run, bent-arm, 50 yd dash, softball throw	Effect 3 reinforcements on motor skill proficiency: Basic motivation, continuous verbal encouragement with & without reward	Continous reinforcement with & without reward best for all groups; For MR best with reward
1974 - Huber	11 students; (age 7-11 yrs); IQs = 53-82; APE class	ABA on multiple baselines (5 phases)	<ul><li>3 Target Behaviors:</li><li>1) behavior only</li><li>2) motor tasks finished</li><li>3) combined</li></ul>	Token reinforcement effect on appropriate behavior & number of motor tasks completed	Tokens aided appropriate behavior & motor task completion
1978 - Schack & Ryan	5 males (age ABA; 14-17 yrs); MR Pre- and Post-	ABA; Pre- and Post-	Ability to learn & retain 2 motor skills (bean bag & ring toss)	Effect of 4 continuous. Social reinforcement, token reinforcement, combined social plus token reinforcement	Motor skills neither learned nor retained. More consistent response with combined social & token reinforcement.

Motor Skill Applied Behavior Reinforcement Studies

Table 14

2002 - Sharp,	52 (M = 30,	ABA;	Target behaviors:	Effect of APE activities	Time spent in physical
Pitetti, Rogers,	F = 22); DD;	Pre- and	1) Healthy fitness	modified to meet students	activity increased during
Bohlken, &	4 Wichita	Post-	(cardio, muscule, &	abilities for 15 weeks	semester. Increased
Abendroth	public schools		body comp)	(1 semester)	fitness levels maintained.
			2) motor skills		Suggested offering PE
			3) time in activities		in schools to students/DD
Note: ABA = applie	ed behavior approc	ich; APE = ad	aptive PE; DD = Developmer	Note: $ABA = applied behavior approach; APE = adaptive PE; DD = Developmental Disabilities; MR = mental retardation; ND = no disability$	dation; ND = no disability

for distance. All groups performed significantly better when active encouragement was added to standard instruction.

Solomon (1969). The effects of motivational strategies on the physical performance proficiency of 81 male participants (aged 14 to 17) with repeated trials, were investigated. Participants were from a public school or institutionalized. Participants were randomly assigned to three treatment groups (one without cognitive disabilities and two with educable cognitive disabilities), and reinforcement subgroups (basic motivation, and continuous verbal encouragement with and without monetary reward). Subgroups were given 10 trials on dependent measures (shuttle run, standing broad jump, 50-yard dash, and softball throw). Results confirmed that continuous verbal encouragement, with or without material reward, produced significantly better performance in all groups. Participants in all groups performed well with continuous verbal encouragement; individuals experiencing cognitive disabilities had the best performance when material reward was added.

*Huber (1974).* Huber conducted a multiple baseline study with 11 students (aged 7 to 11 years) in an adaptive physical education class. The participants were classified as educable (IQs ranged between 53 and 82). The purpose of this study was to explore the effects of a token economy program on controlling appropriate behavior and facilitating the motor task performance of students with cognitive disabilities in an adaptive physical education classroom setting. Tokens were awarded

based on either appropriate behavior and/or the number of motor tasks completed. The research design consisted of five inclusive phases: baseline (intervention on behavior only), baseline two (intervention on tasks completed), and a combined intervention of behavior and tasks completed. Use of token reinforcement resulted in appropriate motor performance and motor task completion.

Schack and Ryan (1978). The effects of a schedule of continuous reinforcement on motor learning and retention in 5 males (aged 14 to 17) with trainable (IQ 25-39) cognitive disabilities were studied. Targeted gross motor skills (beanbag and ring toss) were selected for instruction, performance, and retention during 48 sessions over 12 days. Four reinforcement strategies were used: (a) instruction only, (b) instruction plus social reinforcement, (c) instruction plus token reinforcement, and (d) instruction plus combined social and token reinforcement. While participant response was more consistent with the combined social plus token reinforcement (followed by social reward, token reward, and instruction only), motor skills were neither learned nor retained.

Sharp, Pitetti, Rogers, Bohlken, and Abendroth (2002). The researchers conducted a study with 52 children (30 males and 22 females) with developmental disabilities (such as mild to moderate MR, Down syndrome, autism, and multiple disabilities) recruited from four Wichita public schools. The study tracked the fitness levels of the participants for one school semester (15 weeks) in a physical education

program (*Stepping Out For Fitness*) designed specifically for students with developmental disabilities, and other activities modified to meet the students' abilities. Pre- and post- measures of cardiovascular fitness, muscular strength, body composition, and motor skills were performed. Study results indicated that the amount of time spent in physical activities increased throughout the semester and increased fitness levels were maintained. Researchers suggested that schools should consider adopting a similar physical education program to provide students with developmental disabilities the opportunity to engage in regular physical activities. The suggestion was surprising, given the fact that physical education was mandated for this population in 1975 (Public Law 94-142) and its subsequent amendments and reauthorizations.

## Exercise Intervention Studies for Weight Loss

Exercise designed to increase fitness has a favorable impact on health by maintaining weight and improving cardiovascular function (Auxter & Pyfer, 1985,1989; Bartlett, 2003; Draheim, 2002; Drowatsky, 1971). Table 15 includes a small sample of studies conducted that focused on increased exercise levels to reduce body weight in persons with cognitive disabilities. Body composition was included in some studies.

Ross (1975). A 16-week walking program did not produce significant differences between the mean body fat percentage lost in intervention and control groups. Skinfold thicknesses were measured to

Exercise Behavioral Interventions for Weight Control	tions for Weight Control			
Year & Study	N, Sex, Level	Exercise Weight Loss Program	Measure	Criterion & Results
1975 <b>a</b> - Ross	22 Females (18-43 yrs); Profound; Institution	<ul><li>I = 16 weeks (F = 0): Walking</li><li>to reduce body fat &amp; weight;</li><li>2 groups (control &amp; treatment)</li></ul>	Weight, % BF, skinfolds	Criterion not provided; %BF loss not significant between groups; Mean wt loss: 0
1980 - Skrobak-Kaczynski & Vavik	10 (16 - 31 yrs) Down syndrome	I = 12 weeks (F = 0); Circuit train (1 hr 3 X / week) for BF & weight loss ; No control group	Weight, % BF	Criterion not provided; %BF; Mean wt loss: 1.3 kg (2.63 lbs)
1984 <b>n</b> - Haring & Sawey	24 M & F; MR public school; sheltered workshop	<ul> <li>I = 8 weeks; Compare effect of 2 cardio programs on weight, basic knowledge &amp; fitness: 3 groups</li> <li>(2 exercise, control); 30-50 min, 4 X /week</li> </ul>	Weight, skinfolds, Girth; Cardio; pencil	Criterion not provided; pre- & post- measurements; Good results
1986 - Fisher	17 adult females Mild to moderate	<ul> <li>1 = 8 weeks (F = 0); 2 groups</li> <li>Compared weight loss effects of eating habit change (reinforced)</li> <li>&amp; integrated walking program;</li> <li>No control group</li> </ul>	Weight % BF	<ul> <li>&gt; 20% overweight (obese)</li> <li>Mean Wt Loss: 0.8 kg</li> <li>(1.69 lbs). Reinforced to</li> <li>change eating habits; 1 kg</li> <li>(2.02 lbs) vs 0.6 kg (1.21 lb)</li> </ul>
1990 - Croce	3 males (24 -30 yrs) Severe MR Institutionalized	<ul> <li>I = 12 weeks (F = 0). Reduced diet Weight 500 calories/day &amp; exercise with % BF reinforcement (verbal &amp; token);</li> </ul>	Weight % BF	> 20% over ideal weight; Mean wt loss: 7.73%, 7.7 kg (15.59 lbs); %BF loss = 19.3

Exercise Behavioral Interventions for Weight Control

Table 15

1991 - Pitetti & Tan	12 (7 M, 5 F) (22-28 yrs) 16 weeks Mild MR (1Q 61 <u>+</u> 3) Exercise ( Downs not included	16 weeks Exercise (bicycle ergometer)	Weight	Criterion not provided Mean Wt Loss: F 2.9 kg, M + 0.5 kg
1999 <b>-</b> Frey, McCubbin, Hannigan-Downs, Kasser, & Skaggs	<ul> <li>18: 9 (7 M, 2 F) with mild</li> <li>moderate MR; 9 (7 M,</li> <li>2 F) without MR; Age</li> <li>mean 28.7 yrs.</li> <li>No Down's.</li> </ul>	M, 2 F) with milc Compare runner %BF (MR & ate MR; 9 (7 M, NMR). Runners with MR had nout MR; Age trained for 1 year (some ran the 8.7 yrs. Boston marathon). MR showed n's. no chronotropic incompetence.	Skinfolds; %BF from generalized equations	%BF in runners is low, not obese; Results: (1) %BF not significantly different (Male MR = 14.1< NMR =15.8%) (Female MR 25.3, NMR 19.6)
2001 – - Culphf, O'Connor, 827 (M=25, F=12); adults Vania Sheltered workshop (on & off site)	8.27 (M=25, F=12); adults Sheltered workshop (on & off site)	12 weeks (3 X /Wk) low impact aerobic dance cardio fitness study	BMI Walk time	Down's shorter, higher BMI; Heart rate significantly diff; Music & mats left, not used
2001 - Pitetti & Yarmer	874 children with (268) without MR (606) No Downs	874 children with (268) & Compared aerobic fitness (20m without MR (606) shuttle run) & BMI by gender, No Downs MR, 3 age groups	BMI Laps run VO2 max	Females shorter, higher BMI, fewer laps all ages; Results: MR had lower cardio-fitness, muscle strength, & endurance. Dramatically lower fitness in MR children
2003 - Kozub	7 (M=4, F=30;13-25 yrs; weights 61 to 232 lbs; IQ range 45-68.	7 (M=4, F=30;13-25 yrs; 7 day assessment of activity with weights 61 to 232 lbs; semi-structured caretaker IQ range 45-68. interview.	activity log; fitness test; motivation scale	Lack of social networks & transportation were barriers to activity cited; low levels of fitness; low activity levels
Notes: %BF = percentage body )	fat; MR = mental retardation; l	Notes: %BF = percentage body fat, MR = mental retardation; NMR = not having MR; wt = weight; = = control group	ontrol group	

estimate percentage body fat for the 22 institutionalized females included in this study.

Skrobak-Kaczynski & Varik (1980). Significant weight loss (mean 1.3 kg) was produced during this 12-week (3 times per week) circuittraining intervention for 10 adolescents and young adults (aged 16 to 31 years) with Down syndrome. Percentage of body fat was estimated utilizing height and weight calculations. The study did not include a control group or follow-up to evaluate long-term program effectiveness.

Haring and Sawey (1984). Researchers conducted an unpublished repeated measures study that evaluated the effect of two cardiovascular fitness programs on weight, cardiovascular endurance, basic nutrition, and fitness knowledge. The study included 24 participants (adolescents and adults) with cognitive disabilities (levels unspecified) from a public school and sheltered workshop. Research was conducted in a workplace setting. Participants were randomly divided into three groups (exercise, exercise and nutrition, and control). Individuals with Down syndrome, cerebral palsy, or other contraindicated medical disabilities were excluded from the study. Body size measures performed included weight and girth (upper arm, upper thigh, chest, waist, and hips). Measures of cardiovascular fitness included a step-test and timed one-half mile runwalk. Basic knowledge of fitness and nutrition concepts was assessed with a researcher-designed paper-pencil test.

The intervention consisted of group cardiovascular fitness training

sessions conducted four times weekly for up to 30 minutes. The aerobic training program included warm-up flexibility stretching and up to 20 minutes of continual movement. The group receiving basic nutrition and fitness information met for 20 minutes following each exercise bout. Raw data reflected good response to the training regime for targeted variables. Attendance and dropout rate (for reasons such as needed to work and illness) were problematic. This finding suggested support of other studies concluding that although worksite studies could eliminate transportation problems, a conflict with work schedule might arise that could jeopardize continued participation. The basic research design and intervention methodology were sound, which suggested elements to include in future health-related fitness studies with this population.

Fisher (1986). The effects of two 8-week eating and exercise (walking) approaches to weight loss and body fat reduction were compared. Obesity criterion was defined as >20% overweight. Participants were 17 adult overweight females with mild to moderate cognitive disabilities. The participants were separated into two treatment groups: (a) change of eating patterns with reinforcement resulting in a 1kilogram weight loss, and (b) daily physical activity combined with integrative behavioral weight-reduction resulting in an average 0.6 kilogram weight loss across participants. The daily walking program began with 10-minutes and increased by 5 minutes every week until 30minute daily walks were taken. Weight loss using both interventions was

significant. The intervention of reinforcing changes in eating patterns was the most effective (Fisher, Green, Friedling, & Levenkron, 1976; Loro, Fisher, & Levenkron, 1976). Failure to provide sufficient intervention strategy information and no long-term follow up or control group made full interpretation of the study difficult.

Croce (1990). A 12-week study of combined cardiovascular training, dietary, and behavior intervention was conducted to determine the effects on weight and body fat. Participants were 3 obese institutionalized males (mean body fat 35.4%), aged 24 to 30 years with severe cognitive disabilities. The intervention included verbal reinforcement (for time spent exercising, referred to as staying on task) and a token economy system (earned based on performance) during exercise sessions. No control group was included in the study for comparison of results. The intervention included a daily 500-calorie reduction in food intake; total daily calories were not reported, nor how the caloric reduction was made (such as no dessert). The cardiovascular training component of the intervention consisted of 1-hour exercise sessions of unspecified frequency. The exercise sessions began with a 15minute warm-up (calisthenics), followed by 30 minutes of vigorous aerobic exercise (15 minutes on a stationary bicycle and 15 minutes on a motorized treadmill for brisk walk/run), and concluded with a 15-minute cool-down. Research assistants trained in adaptive education techniques monitored intensity and duration of the exercise sessions.

Croce reported mean weight loss of 7.73% with a 19.31% reduction in body fat. The researcher concluded that body fat and weight could be reduced in adults with severe cognitive disabilities using diet, exercise, and behavioral techniques. Pitetti, Rimmer, and Fernhall (1993) rationalized that without a control comparison group, a placebo effect could be responsible for the results.

Pitetti and Tan (1991). The researchers conducted a 16-week study to improve the cardiovascular fitness of 12 (7 males and 5 females) adults with mild (mean IQ =  $61 \pm 3$ ) cognitive disabilities, aged 22 to 28 years. The participants were recruited from 2 local sheltered workshops and vocational training centers. Individuals with Down syndrome were not included in the study. An exercise room was created at the worksite, outside the work area. Participants that chose to exercise when asked, were escorted there. A goal of the self-regulated program was to determine if persons with cognitive disabilities would exercise at an intensity needed to improve cardiovascular fitness without prompting (Wanlin, Hrycaiko, Martin, & Mahon, 1997). Minimal supervision was included (exercise level instructions were given with no prompting or verbal encouragement while exercising). Duration and intensity guidelines from the American College of Sports Medicine (1991) were followed. Intervention included aerobic training (bicycle ergometer) three times per week. The program consisted of a 3-minute warm-up, followed by bicycle aerobic exercise (increased from 12 minutes in the first week

to 25 minutes during the last week), and ended with a 3-minute cooldown. Exercise sessions were conducted at between 50% and 70% VO2 max (weeks 1 to 2 at 50%, weeks 3 to 12 at 60%, and weeks 13 to 16 at 70%). Individual peak VO2 was determined by pre-exercise stress test.

Results included a 16% improvement in cardiovascular fitness. Pooled data from all participants revealed no significant changes to body weight or body fat percentage. When results were compared by gender, researchers noted that female participants had a significant reduction in body fat percentage (from 30.9% to 27.9%), resulting from exercise alone. Men did not have a reduction in body fat, perhaps due to their low baseline (15.3%). The 6-month follow-up revealed that exercise bicycles left at the worksites had not been used and participants' cardiovascular levels had returned to pre-intervention levels.

Researchers concluded that study participants were not motivated to exercise on their own. This issue is also common among individuals without disabilities. Recent research has revealed that activity has an inverse relationship with age; age-related trends were better predictors of activity than motivation (Kozub, 2003; Sallis, Prochaska, & Taylor, 2000). Pitetti and Tan (1991) stated that a daily time for escorted exercise had to be allocated to make a change in lifestyle that included activity. These findings should be viewed carefully, with consideration given to real life work situations. Economic and time constraints may have entered into participants' decisions to abandon exercise during the workday, rather

than motivation. Merely leaving exercise equipment at the workplace research site doesn't automatically provide an opportunity to exercise.

Worksite employers, in general, do not normally excuse employees from their jobs (paid or unpaid) to exercise; an arrangement that allowed employees to take part in research during the workday, would be an exception. Poverty, levels of unemployment, and poor job retention rates are high among persons with disabilities (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, D., 1990; Funk, 1992; Haring, 1987; Haring, Lovett, & Smith, 1990; Flexer, Simmons, Luft, & Baer, 2001). Many individuals with disabilities work part-time in sheltered workshops that pay on a piece-meal basis linked to contract productivity rates. These individuals may fear losing their hard-to-find jobs and pay, were they to take an exercise break.

Even though the study focused on self-regulated exercise, study personnel helped participants get to the exercise room, and started their exercise sessions; only reinforcement was not provided. The structured research protocol sequence utilized was discontinued. Operant conditioning to continue or self-initiate exercise was not included in the study. Although exercise machines were left, no provision was made for starting daily exercise regimes or giving assistance, if needed. These two factors are reasons exercise clubs and personal trainers are popular for many persons without disabilities that start and strive to continue exercise regimens. Incidental learning and generalization, common

problems among persons with cognitive disabilities, rather than lack of motivation, might have contributed to participants' failure to continue exercise sessions (Stainback & Stainback, 1987; Stainback, Stainback, & Strathe, 1983; Turnbull et al., 2004; Vaughn, Bos, & Lund, 1986).

Frey, McCubbin, Hannigan-Downs, Kasser, and Skaggs (1999). This study included 18 participants (14 males, 4 females) that were trained runners. The study compared the cardiovascular fitness of matched runners with mild to moderate disabilities (n = 9, 7 males and 2 females; mean age 28.7  $\pm$  7.4, range 15 to 40; mean weight = 67.0  $\pm$  11.7 kg) and without (n = 9, 7 males and 2 females; mean age  $29.1 \pm 7.5$ , range 17 to 43; mean weight =  $68.7 \pm 8.8$  kg). The etiology of participants was not reported, however, persons with Down syndrome were not eligible. Skinfold thickness was measured at three sites (triceps, subscapular, and abdomen) to calculate the body composition of participants using generalized regression equations for men (Lohman, 1981) and women (Jackson, Pollock, & Ward, 1980) (Lohman, Boileau, & Massey, 1975; Lohman, Rocke, & Martorell, 1988). No significant differences in body composition between the two groups were identified in his study. The mean derived body fat percentage for males with cognitive disabilities (14.1, SD 7.3) was lower than for males without (15.8, SD 3.0). The mean body fat percentage for females with mild cognitive disabilities (25.3, SD 6.8) was higher than for females without (19.6, SD 1.3).

It has been suggested that chronotropic incompetence, in persons with cognitive disabilities, caused early-onset cardiorespiratory disorders (consistent low maximal heart rate) that contributed to low VO2 max volumes (Fernhall, 1992, 1993; Fernhall, et al., 1998; Fernhall, Millar, Pitetti, Henson, & Vukovich, 2000; Fernhall, Millar, Tymeson, & Burkett, 1990; Pitetti & Campbell, 1991). Results of the study did not find chronotropic incompetence displayed by participants.

The cluster sample in this study was probably atypical of persons with MR, because all participants had participated in a running program for a minimum of one year; some had run the Boston marathon. Previous research has informed us that runners often present a lower body fat percentage than the general population. It is unlikely that participants experienced concomitant physical disabilities that frequently occur in many individuals with cognitive disabilities.

*Culphf, O'Connor, and Vanin (2001).* The purpose of this workplace study was to determine the effects of a low-impact aerobic dance program (12-weeks, 3 times per week) on the cardiovascular endurance of adults with cognitive disabilities. Music was used in the program to increase exercise adherence (Hume & Crossman, 1992; Rimmer, 1994). A certified aerobic dance instructor, certified athletic trainer, and facility staff were present at all sessions. The 27 adult participants (15 males and 12 females; mean age = 39 years) worked in a sheltered workshop. Two groups were formed: (a) control group, with members working offsite

(7 males, 5 females; 3 with Down syndrome); and (b) intervention group, training onsite (8 males, 7 females; 4 with Down syndrome).

BMIs for both groups were similar, pre- measurements were not repeated post-intervention (control group mean =  $33.9 \pm 6.3$ ; treatment group mean =  $31.6 \pm 8.9$ ). In both groups, females were shorter, with higher BMIs than males, and all individuals with Down syndrome had higher BMIs and were shorter. Repeated measures of endurance were collected 5 times using the Rockport Fitness Walking Test (pre-, probes, post-, and follow-up). Results indicated that post- walk time differences between and within group, using independent t-tests and ANOVAs, were not significant. Effect size determined by eta squared was minimal (0.05), and power was (0.15). The difference in heart rate was significant within and between groups, and took a minimum of 8 weeks exercise to increase.

Researchers stated that participants enjoyed the program. Music and exercise mats left onsite after program were not used. It was noted that good teachers with direct involvement were needed to facilitate future exercise (Benner & Cagle, 1987; Bigge, 1991). The researcher recommended use of aerobic dance programs as a recreational activity to increase cardiovascular fitness in individuals with cognitive disabilities.

*Pitetti, Yarmer, Fernhall (2001).* This study compared the aerobic fitness and BMI of 874 children and adolescents (aged 8 to 18) with mild (268; 169 males, 99 females) and without (606; 289 males, 317 females)

cognitive disabilities. The purposive sample was from a designated metropolitan area. Some participants were from a camp (n=230), a local life skills center (n=32), or from inclusive physical education classes (n=6). Participants were split into 3 age groups (8 to 10 years, 11 to 14 years, and 15 to 18 years), by gender and presence of cognitive disability. Individuals with Down syndrome, congenital cardiovascular problems, other medical contraindications to exercise, or taking medications affecting the heart, were excluded from the study.

The 20-meter shuttle run was used to estimate laps run. VO2 max was predicted with regression formulas (Guerra, Pitetti, & Fernhall, 2003). Only the body composition portion of the study was included in this review. Height and weight measurements were used to calculate BMI. Statistical significance was set at p < .05 for all analyses. Females aged 8 to 10 were significantly shorter, had significantly lower peak VO2, and ran fewer laps; their BMIs were higher, but not significantly so. In this age group, males with cognitive disabilities were shorter, and ran fewer laps than males and females without disabilities, although these findings were not statistically significant.

Participants with disabilities in the 11 to 14 age group ran fewer laps, were shorter, and weighed more than their non-disabled peers. The only significant findings for this age group were the fewer numbers of laps run and lower peak VO2 in females with cognitive disabilities. In the 15 to 18 age range, participants with disabilities were heavier and

ran fewer laps, with only female findings significant. Other findings of interest in this age range included: (a) significantly lower VO2, and higher BMI in females with disabilities; and (b) males with disabilities out performed the females without disabilities slightly, although not statistically significantly.

The fewer number of laps run by individuals with disabilities was indicative of lower cardiovascular fitness, lower muscle strength and endurance, and dramatically lower physical fitness. Higher BMI has been shown to negatively influence running performance in children and adolescents with cognitive disabilities (Fernhall & Pitetti, 2000).

*Kozub (2003).* Extensive information was gathered on 7 adolescents diagnosed with cognitive disabilities (males and females; aged 13 to 25 years; height ranged from 53 to 68 inches; and weight ranged between 61 and 232 pounds). Participants displayed low fitness scores, although they had no known physical or medical problems that would interfere with activity. During the 7-day investigation, participants met with the researcher twice to determine physical activity patterns. Physical activity and movement are related to health in the general population. Caregiver and parent interviews, motivation, fitness levels, and physical activities were triangulated in this study. Measures included were: individual activity monitors (RT3), Pictorial Motivation Scale, Brockport Physical Fitness Test, Children's Physical Activity form for coding activity, external regulation of activity by a teacher, and semi-

structured interview (8 items) to collect qualitative information from caregivers about their children's activities.

Analysis of data gathered, revealed that patterns of activity were short, moderately strenuous, and occurred during the afternoons (consistent with after school and community recreation/leisure timeframes). The levels of activity reported tended to be inadequate to maintain or improve cardiorespiratory endurance. An inverse relationship was demonstrated between age and physical activity patterns, consistent with prior research (Sallis, Prochaska, & Taylor, 2000). Independent living skills for social arenas (such as telephone use, and ability to access leisure time activities) were perceived as the most important independence skills taught in school by caretakers. Parents considered lifetime fitness activities of interest to their children (basic exercises, recreation/leisure skills at an appropriate level, and sports, not necessarily competitive), and health information, the most important skills taught in physical education classes (Wehman, 1978; Wehman & Marchant, 1977).

Although caregivers stated that physical activity was important for their children socially, few caretakers had time for it in their personal schedules, thus, failing to provide a role model in this area. Researchers also noted the lack of related activity patterns between caretakers and participants. The most often stated barriers to engagement in activities included: (a) whether friends took part; (b) lack of motivation; (c) not

liking an activity; (d) transportation issues [such as inability to drive and need for public transportation]; and (e) need for a social network. The existence of transportation and social network issues was supportive of research by Modell and Valdez (2002).

Kozub (2003) stated that families should create opportunities to engage in physical activities together, suggesting that physical educators could provide support and positive impact in this area. Kozub stated that persons with disabilities needed instruction in self-determination skills and a wider range of activity choices that considered fitness and ability levels (including lifetime and community-based options), with transportation arranged. Interestingly, instruction in the rules and procedures for sports activities was not addressed. Kozub suggested that future research should be conducted to determine if physical activity choices would impact motivation and participation.

#### Lessons from Cardiovascular Fitness Studies

Although measuring change in cardiovascular fitness was not a goal of the current study, conclusions from previous studies in this area have provided valuable information to researchers concerned with the health and fitness of individuals with disabilities. Cardiovascular endurance has been the most frequently researched component of health-related fitness; effect sizes support the positive health benefits of exercise (Chanias et al., 1998). Prior cardiovascular research reported that evaluations were more valid and reliable when conducted in a

familiar, comfortable setting, by personnel that participants had seen and were comfortable having present (Pitetti, Rimmer, & Fernhall, 1993). Participants often appeared more comfortable with a staff member close by. It was reported that interventions and evaluations should consider individual's differing walking speeds, walking capacity, ambulatory problems, poor coordination, anxiety, stepping cadence, and pedaling rhythm (Montgomery, Reid, & Koziris, 1992; Reid, Montgomery, & Seidl, 1989; Seidl, 1998; Seidl, Reid, & Montgomery, 1987). Cardiovascular researchers have noted that desired tempo during step-test exercise was difficult to set and maintain; motivation was known to cause wide variability, especially for persons with MR (Cohen, 1985; Fernhall & Tymeson, 1988; Lavay, Reid, & Cressler-Chavez, 1990; Seidl, Montgomery, & Reid).

Certain testing protocols may over estimate actual VO2 max in persons with Down syndrome by 30% (Pitetti, Climstein, Campbell, Barrett, & Jackson, 1992). Individuals with Down syndrome have demonstrated peak heart rates 20 beats per minute below other persons having cognitive disabilities (Pitetti et al.); reasons had not been studied at that time. Over estimation of fitness levels could occur using formulas extrapolated from those used to estimate maximal heart rates in the general population, which might be inappropriate due to the significantly lower heart rates exhibited by many persons with cognitive disabilities (Fernhall et al. 1989, 1990; Fernhall & Tymeson, 1987; Pitetti et al.

1989, 1992a; Pitetti & Tan, 1990, 1991). Literature suggested that extrapolation formulas developed for persons without disabilities be validated for a specific population, prior to use (Pitetti, Rimmer, & Fernhall, 1993).

### Run Performance

Physical work capacity, recently measured by run performance, has received health research interest because of its connection to daily living activities, subsequent morbidity, and mortality rates linked to cardiovascular disease (Blair et al., 1989; Calle, et al., 1999; Fernhall & Pitetti, 2001; Janicki & Breitenbach, 2000; Janicki & Seltzer, 1991; Ljungkvist, 2000; Peters et al., 1983; Pitetti & Fernhall, 2004; Wei et al., 1999; Williams, 1997, 1998). Adolescents with cognitive disabilities have consistently displayed poor performance on run performance tests (20meter shuttle run, 600-yard, and mile run), sometimes 50% less than levels expected for age and gender-matched nondisabled peers (Fernhall et al., 1996a; Fernhall & Pitetti, 2000; Fernhall et al., 1998; Fernhall et al., 2000; Pitetti, Yarmer, & Fernhall, 2001). High BMI and weight levels have shown to negatively impact cardiovascular capacity. Research studies have included these measurements as mediating or subject variables for demographic and descriptive use, rather than to determine outcome results (Daniels, Khoury, & Morrison, 1997; Gallagher et al., 1996; Himes, 1980).

Pitetti and Fernhall (2004). Researchers conducted two studies

with 594 adolescents (aged 11 to 18 years, matched on age and gender), to compare the influence of mild cognitive disabilities and Down syndrome, on running performance using the 20-meter shuttle run. Study 1 divided 514 participants into two groups: 119 (62 males, 57 females) with Down syndrome, and 395 (244 males, 151 females) without. Study 2 included 475 participants to compare the performance of individuals with cognitive disabilities, but without Down syndrome from study one (n = 395), to that of individuals without cognitive disabilities (n = 80, 41 males and 39 females; matched on age, gender and BMI). Results of pooled studies revealed that persons without cognitive disabilities demonstrated the highest run performance, and individuals with Down syndrome the lowest.

#### Motivation

Lack of motivation to exercise was mentioned in literature reviewed. Millar, Fernhall, and Burkett (1993) studied persons with cognitive disabilities exercising individually, following a routine researchers had developed. They noted constant exhortation was necessary to keep participants moving during sessions; the issue was viewed as lack of motivation. During isokinetic strength exercise studies, Pitetti and Tan (1990) also indicated participants lacked motivation to take part in test. These researchers found that motivation and test performance improved when assessments were repeated on separate days, providing participants an opportunity to adjust to something

unfamiliar. Incidental learning and generalization to an unfamiliar situation or understanding something unknown is difficult for most persons with cognitive disabilities.

Age-related trends were found to be better predictors of engagement in activity than motivation, with an inverse relationship existing between age and activity (Sallis, Prochaska, & Taylor, 2000; Kozub, 2003). Participation in activities alone, at a level an individual was not interested in and did not select, with reinforcements not valued, could result in issues that might be confused with lack of motivation. Lack of motivation to exercise is not isolated to persons with disabilities. Individuals without disabilities commonly slack off during exercise programs, often addressing the issue through authentic social exchange and reinforcement found in exercise classes, gym visits, exercising with a friend, and personal trainers. These avenues are not available to many persons with cognitive disabilities.

### Endurance

Millar, Fernhall, and Burkett (1993) recognized that familiarity with an activity (such as setting, understanding the process, equipment, and personnel) could result in reduced anxiety, and explain increased exercise endurance (such as ability to walk longer times on treadmill) without making gains in VO2 max. Researchers reasoned that exercise programs of short duration might be ineffective at keeping heart rates at the level of intensity needed to improve aerobic fitness measures.

### Down Syndrome Specific

The cardiovascular fitness of individuals with Down syndrome was considered substandard when compared to individuals with cognitive disabilities not experiencing Down syndrome (Pitetti, Climstein, Campbell et al. 1992). Increase in height was slower and weight gain quicker for children with Down syndrome (Cronk et al., 1988). Lower extremity problems made these individuals less able to participate in physical activities (Cronk et al., 1988).

Pitetti, Climstein, Mays, and Barrett (1992) compared the strength of elbow and knee extension, and flexion of young adults with cognitive disabilities, with and without Down syndrome, to sedentary nondisabled persons. Persons with cognitive disabilities demonstrated lower leg strength than sedentary persons without disabilities. Individuals with Down syndrome demonstrated poorer leg strength than their peers with cognitive disabilities, but without Down syndrome (Horvat, Croce, Stadler, & Pitetti, 1996).

## Practice and Performance

As noted earlier, Pitetti and Tan (1990) found that performance on isokinetic strength tests could improve when a test was given twice on successive days, with the second score usually the better. Researchers stated that the second effort should be reported.

*Chanias, Reid, and Hooper (1998).* The researchers conducted an often-cited meta-analysis of primary research focused on the effects of

health-related physical fitness exercise programs for individuals with cognitive disabilities performed between early 1979 and April 1996. To be deemed relevant to the study, the following selection criteria had to be met: (a) at least one of the five components of health-related fitness had to be included; (b) participants had to be diagnosed at varying levels of cognitive disabilities; (c) exercise-only programs; (d) data analysis had to include means, standard deviations, and number values; (e) intervention maintenance and follow-up was mandatory; (f) sample size had to include 6 or more participants; and (g) exercise treatment studies had to be administered by the researcher. Studies were excluded from the meta-analysis if: (a) fitness measures used were deemed inappropriate by researchers [such as 300-yard run and mean daily distance]; (b) persons identified with Down and other syndromes, concomitant conditions, or other clinical diagnoses were included; (c) exercise was combined with another treatment (such as dietary intervention); and (d) program evaluations were conducted by organizations [such as Special Olympics]. Fifty studies were located after a thorough search of journals and dissertations. Twenty-nine failed to meet the selection criterion and were eliminated from the analysis. Twenty-one studies were included in their meta-analysis.

Although meta-analysis findings were valuable (such as effect size to facilitate comparison), limitations to generalization could occur if results were not representative of the typical population of persons with

cognitive disabilities. Many individuals with disabilities were excluded from the meta-analysis, such as persons with concomitant conditions that occur frequently in this population, especially in persons with lowincidence diagnoses classified below the mild level of retardation. An investigation of studies excluded from this meta-analysis could glean valuable information.

Body Composition in Persons with Cognitive Disabilities

Individuals with cognitive disabilities experience a high prevalence of obesity and chronic illness as summarized in Table 5 (Cronk, et al., 1988; Horowitz et al., 2000; USDHHS, 1996). Body size studies on individuals with disabilities often focused on weight (body mass) change and did not consider body composition, which is more closely linked to health, a variable of interest. Other measures should not be overlooked. The usefulness of waist circumference in monitoring health recently came to light with the finding that increased waist circumference, even in persons of normal weight, can be a marker for increased risk of type 2 diabetes, hypertension, and cardiovascular disease (Crespo & Arbesman, 2003). Given the recent emphasis on improvement of health outcomes in this population, it appears that body composition would appropriate research focus, rather than weight alone (USDHHS 1995, 1996).

### Measurement of Body Composition

Interest in the health-related fitness of individuals with cognitive disabilities has increased. While a variety of measures exists to estimate

body composition in the general public, locating validated measures for individuals with cognitive disabilities is problematic; methods used have been antiquated and inappropriate (Frey et al., 1999; Mathews, 1968; Wilmore, 1969; Wilmore, & Behnke, 1970). Researchers have stated the paucity of body composition studies with this population may be due to the lack of proven skinfold formulas and measurement instruments (Kelly & Rimmer, 1987; Kelly, Rimmer, & Ness). Most researchers studying persons with cognitive disabilities continue to utilize anthropometric measures and classify these individuals with standards normed on individuals without disabilities. A need exists to explore new methods to assess body composition in individuals experiencing cognitive disabilities (Burkett & Phillips, 1994; Chanias et al., 1998; Pitetti, Rimmer, & Fernhall, 1993).

## Anthropometric Measures

Educational researchers commonly use anthropometric measurements (such as skinfolds, height, weight, girth) alone or in combination (such as BMI and standardized tables). Accurate measures of this type are usually easy to perform with little training or practice, and are inexpensive, noninvasive, safe, and expedient, with classification data easy to access (Keys et al., 1972). Standardized weight for height tables and growth charts normed on the general population are probably not appropriate for individuals with disabilities; characteristics of certain syndromes include short stature, weight problems, and links to chronic

illnesses (Valman, 1980). Although a few growth charts have been developed, they were not validated for children with various syndromes. True body composition (measured by body density) is a more difficult variable to measure than BMI body fat percentage estimates. Research using new technology to more accurately measure body composition is clearly indicated. Table 11 includes risk factors for obesity-associated diseases that were referenced to BMI, girth, gender, and child or adult status.

*Weight.* This anthropometric scale measure of total body mass (in pounds or metrics) does not address fractionation of body mass (muscle, bone, and fat). Weight considers all components of the body to be the same. It does not account for the difference in fat and muscle density and may not accurately acknowledge healthy improvements brought about through exercise and nutrition. Although weight has been used as the dependent variable in most body size studies with this population, the need to focus on other measures related to health (such as body composition) is clearly indicated.

Anthropometric Measurement Combinations. Use of multiple forms of measurement lends validity and reliability to studies. Formulas and measures to estimate weight level status and body composition (body fat percentage) often vary with age and gender: (a) standardized tables [weight for height and BMI]; and (b) derived regression equations to determine body density. Bray (1979) defined obesity as weights 20% or

more above the average desirable weight ranges on standardized heightweight tables by gender. Body fat percentages (BMI) greater than 30% in women and 25% in men are obesity criterions that have varied little since 1975 (Bray, 1975; Bray, Greenway et al., 1978). Literature reviewed found obesity to be more prevalent in individuals with cognitive disabilities than the general population.

Limitations exist when body composition is estimated with anthropometric measurements applied to standardized weight for height tables. Individual body make-up (such as bone structure and muscular build) was not considered when standardized tables were developed (McArdle, Katch, & Katch, 1991). Large errors have been found when body fat percentage was estimated by plotting height and weight on standardized tables (Katch & Katch, 1980). No validated tables exist for persons with cognitive disabilities or genotype specific syndromes (such as Down syndrome, Prader-Willi syndrome, and fragile-X syndrome). Rotatori and Fox (1980) cautioned that tables normed on the heights and weights of individuals in the general population might inaccurately designate overweight and obesity in individual with cognitive disabilities having syndromes.

Most research reviewed for individuals having cognitive disabilities used BMI to estimate percentage body fat, stating: (a) it is internationally based, a good index of overweight and obesity during childhood and adolescence (Cole et al., 2000b); and (b) BMI during childhood and

adolescence are good predictors of adult obesity (Flegal, 1999). Some studies reviewed also used standardized weight for height tables as the criteria for obesity.

*Circumference (Girth).* These measurements were performed with a tape measure at one or more locations (such as waist and forearm), and used singularly or in combination with other measurements (such as height and weight). Waist girth was considered an indicator of adipose tissue, associated with risk of developing cardiovascular disease (CDC, 2004; Crespo & Arbesman, 2003). Nomograms were preformatted charts, similar to standardized weight for height tables, using two types of anthropometric measures that intersect, providing a ratio representing body fat percentage (such as waist girth to height, and hip girth to height). Literature reported that problems with nomogram construction have resulted in highly inaccurate derived body fat estimates when compared to direct calculations (Himes, 2001; Kahn, 1991).

*Skinfolds.* In practice, skinfold measures continue to be widely used to estimate body composition because of low cost and relative ease in obtaining. Literature reviewed indicated that problems have occurred while obtaining these measurements studies (Cottrell, 1985; Himes, 2001). The noninvasive process to measure subcutaneous fat thickness (skinfolds) is thought to be more specific to adipose tissue than measures of body mass (such as weight and BMI) (Bouchard & Johnston, 1988; Himes, 1980, 2001; Roche et al., 1981). The skinfold method to estimate

percentage of body fat is frequently used to monitor and track changes in the body composition of athletes preparing for competition (Woolford & Gore, 2004).

Pressure calipers most often used to measure the thickness of a double fold of skin and adipose tissue were Lange (measure to 65 mm) and Holtain (measure to 50 mm) (Himes, 2001). Percentage of body fat in persons with cognitive disabilities was estimated using individual skinfold sites (such as triceps), a sum of up to seven sites (such as biceps, triceps, subscapular, abdominal, supraspinale, front thigh, and midcalf), or in combination with girth (Fox, Burkhart, & Rotatori, 1983; Kelly, Rimmer, & Ness, 1986; Nordgren, 1970, 1971; Polednak & Auliffe, 1976; Ross, 1995). Literature suggested that skinfold measures were one of the best estimates of body fat content, especially when several body regions were averaged (Durnin & Rahaman, 1967; Durnin & Womersley, 1974). Researchers noted that skinfold formulas provided good estimates of body fat percentage for a large institutionalized sample of persons experiencing cognitive disabilities (Kelly, Rimmer, & Ness, 1986; Kelly & Rimmer, 1987).

Problems encountered using skinfold measurements included: (a) possible 200% measurement errors when taken by untrained personnel (Katch & Katch, 1980); (b) wide variation in measurements obtained, due to technique and site selection [Bray, 1978; Shaw, 1986]; (c) errors in measurement compounded by obesity [Bray; Shaw]; (d) idiosyncratic

difficulties associated with taking measurements of adults with cognitive disabilities [Cottrell, 1985; Pitetti, Rimmer, & Fernhall, 1993]; and (e) skinfold thickness too large for calipers [Himes, 2001].

#### Laboratory Measures

Use of specialized equipment and training are earmarks of laboratory measures (such as hydrostatic weighing, air displacement [Bod Pod], dual energy x-ray absorptiometry [DEXA], and near infrared interactance [NIR]). Test costs and location of equipment (such as university, research facilities, pro athletic facilities, hospital, and health club), make these methods to measure body composition inaccessible to many individuals, unless they are taking part in a research study. The newest methods to measure body density have been mostly unavailable for use with minors and persons experiencing disabilities. No body size or physical fitness studies for persons with cognitive disabilities, using the newest methods available to determine body composition, were located in literature reviewed. Additional barriers to their use in this population include inability to secure university IRB approval (personal communiqué with D. A. Fields, Ph.D. in February, 2004).

Bod Pod, DEXA, and NIR are considered ideal tools for measuring body composition in individuals with disabilities (University of Georgia, 2004). Many clinicians consider DEXA the new gold standard (replacing hydrostatic weighing) for accurately estimating body composition (Horodyski, 2003). Clinical laboratory methods to measure body fat

percentage that invade the body (such as total potassium, total water, and other blood-generated assessments), are not readily available, nor are they accepted as part of a nutritional, or health-related fitness assessment (Roche, Siervogel, Chumlea, & Webb, 1981).

Hydrodensitometry or Hydrostatic Weighing. This method of determining body density utilizes water displacement. Conventional techniques include total body submersion, with air in full lungs exhaled until empty while underwater. Because individuals are taught to inhale before going underwater, expiring breath maximally underwater to residual volume may be difficult and threatening for many persons with cognitive disabilities (Burkett & Phillips, 1994; Rimmer, Kelly, & Rosentswieg, 1987). Only two studies were located that used underwater weighing with persons having cognitive disabilities to predict the percentage of body fat and examine the effectiveness of regression formulas (highest correlation was r = 0.89, obtained by Rimmer, Kelly, & Rosentswieg, 1987) (Rimmer, et al.; Ovalle, Cole, Climstein, & Dunn, 1991). The two techniques used for hydrostatically weighing this population were: (a) inhaling to total lung capacity [Rimmer et al.]; and (b) head not submerged [Ovalle et al.]. Burkett and Phillips stated that hydrostatic measurements with persons having cognitive disabilities tended to be inaccurate. Pitetti, Rimmer, & Fernhall (1993) provided recommended procedures to use hydrostatic weighing with this population.

Use of regression equations to predict percentage body fat from anthropometric measurements was suggested when laboratory measurements were unavailable (Horodyski; Katch & Katch, 1980; Kelly & Rimmer, 1987; Pitetti, Rimmer, Fernhall, 1993; Siri, 1956). Kelly and Rimmer developed a derived equation for use in predicting hydrostatic percentage body fat in adult males with Down syndrome from anthropometric measures (Pitetti, Rimmer, & Fernhall). Horodyski developed an equation to predict DEXA percentage body fat in persons without disabilities, using the sum of 5 or 6 skinfolds (he recommended using 5). Siri's formula to predict body fat percentages comparable to hydrostatic weighing for swimmers, has been validated for use with the general population and was frequently referenced in literature reviewed. Certain generalized regression equations developed on individuals without disabilities have been found suitable for use with individuals having disabilities, by gender: (a) for males [Durnin & Womersley, 1974; Jackson & Pollock, 1978]; and (b) females [Jackson, Pollock, & Ward].

*Air displacement.* Bod Pod is perhaps the newest electronic tool that uses air displacement to measure body volume (University of Georgia, 2004). This measure of body composition is quick (5 to 8 minutes per person) and does not require getting wet, however, the participant has to remain still, with arms placed in their lap, and breathe normally. Any movement or change in breathing pattern can affect the

results. Persons being tested are required to wear spandex shorts and a swim cap, and be hydrated, with no increases in muscle temperature. When guidelines are followed and the accepted  $\pm$  3% measurement error used, Bod Pod has shown to be highly correlated with hydrostatic weighing (r = .93) (McCrory, Gomez, Bernauer, & Mole, 1995). The cost of Bod Pod body composition assessment was estimated at between \$40 and \$65 per person (University of Georgia). The machine is usually available only in research laboratories or pro and college athletic facilities.

*Dual Energy X-Ray Absorptiometry (DEXA).* This technology is used to assess bone mineral density and has proven to have a low 1% precision error (Felix, McCubbin, & Shaw, 1998). The technology for DEXA is based on measuring three elements of body composition (muscle, bone mineral, and fat). The procedure is relatively new and uses a two X-ray energy source to measure the three body composition elements. A body scan of tissue is produced with DEXA that represents the whole body or regional area and provides estimates of muscle, bone mineral, and body fat. The lean muscle mass is tissue independent of bone. During the approximate 12-minute body scan, the individual lies still, in a supine position on a table resembling one used for X-rays. DEXA is considered more accurate than two-element models (fat mass and lean mass) for estimating body composition as indicated by multicomponent validation (r = 0.92, SEE + 3.4%) (Felix, McCubbin, &

Shaw). No special clothing or preparation is required for the assessment. The use of radiation, even though exposure is low, makes it difficult to receive IRB approval for use with protected populations, such as minors and individuals with cognitive disabilities. This technology was stated as a feasible measure for determining body composition in individuals with cognitive disabilities, which may be less difficult than hydrostatic weighing (Felix, McCubbin, & Shaw). DEXA's high assessment cost (estimated at close to \$300 per person [University of Georgia]), and location (found at universities or research facilities), make it prohibitive.

*Bioelectrical Impedance (BIA).* It is thought that this measurement method holds promise for use with individuals having cognitive disabilities, although it was not used with this population prior to 1995 (Lukaski, Bolunchuk, & Siders, 1986; Lumbardi, Troxel, & Menon, 1986). Burkett and Phillips (1994) compared this method to NIR, and a combination of skinfolds and girth. The instrument was calibrated for each individual according to manufacturer's instructions. Sex, height, weight, and activity level were programmed into the machine to calculate percentage body fat. Pre-test instructions included: no alcoholic beverages 24 hours prior, no exercise or smoking 4 to 6 hours prior, and no eating 2 to 4 hours prior to the test. Each subject was supine on a mat, with legs apart so inner thighs did not touch, current-charged electrodes were placed distally on dorsum of right hand and foot, and detector-electrodes were placed proximally on right hand and foot

(Burkett & Phillips).

Near Infrared Interactance (NIR). Assessment of body fat with this method is based on light absorption, reflectance, and near infrared spectroscope. The method is considered fast, convenient, safe and noninvasive. A computerized spectrophotometer with a scan and probe is used in NIR. The probe is placed onto a selected body site (such as the bicep) and its infrared light is passed through fat and muscle then back to the probe (University of Georgia). The Futrex 5000 is new technology that uses NIR technology. This assessment considers individual information such as height, weight, gender, age, frame size, and activity level. Body density measurements are obtained with NIR and entered into manufacturer predication equations to provide body fat and lean tissue percentages. While NIR has been considered the most accurate method of assessing body fat (University of Georgia), the Futrex 5000 has demonstrated a +4% error when assessing body fat at extreme ranges in underweight or obese persons (in persons with 8% fat, body fat was overestimated by 4%; in persons with greater than 30% fat, body fat was underestimated by 4%) (McLean & Skinner, 1992). When Mclean et al. compared NIR to skinfold assessment, using hydrostatic weighing as the criterion, skinfold measurement was found to be more accurate. Individual NIR assessment costs are estimated at between \$20 and \$40. NIR is available with Futrex 5000 at weight loss centers, health clubs, and some bariatric medical practices (University of Georgia).

# Body Composition Studies

The literature review revealed that weight change has been more frequently studied than body composition in individuals with cognitive disabilities. In some studies previously reviewed, body composition was provided as a subject variable in the demographic description of participants, rather than as a variable of interest. A brief overview of six studies is included in Table 16.

#### Fox, Burkhart, and Rotatori (1983b)

Researchers investigated how to appropriately classify adults with cognitive disabilities, as obese. Participants included 84 adults (40 males and 44 females; mean age 31 years) working in a sheltered workshop. Anthropometric measures (triceps skinfold thickness, height and weight) were performed on participants; correlation was seen between genders. When height and weight tables alone were used to determine obesity, 22.5% of males and 13.7% of females were misclassified as obese.

#### Rimmer, Kelly, and Rosentswieg (1987)

Accuracy in predicting percentage body fat in 57 institutionalized adults (32 males and 25 females; aged 18 to 40 years), diagnosed with moderate to severe cognitive disabilities, was the focus of this research study. Measurements performed were skinfold, girth, and hydrostatic (underwater) weighing at total lung capacity (the criterion measure).

16	
Table	

Body Composition Studies for Individuals with Cognitive Disabilities

Year & Study	N, Sex, Level	Study Need	Measure	Measurement Results
1983 - Fox, Burkhart, & Rotatori	84 (M=40, F=44) Aduits (mean = 31 yrs) sheltered workshop	Way to classify obesity in persons with MR	Skinfold (triceps); Height, Weight	Height - weight table alone can misclassify males (22.5%) and females (13.7%) as obese; Gender correlation of measures exists.
1987 - Rimmer, Kelly, & Rosentswieg	57 (M = 32, F = 25) (aged 18-40 yrs); moderate to severe; institutionalized	Way to accurately predict body comp %BF in persons with MR. (Compared derived generalized regression equations to estimate % BF)	Skinfold, girth, hydrostatic weight to total lung capacity	<ol> <li>Using paired t-test. Difference not significant between actual residual volume &amp; constant value (M=1300 ml, F=1000). 2) Expiring breath procedure hydrostatic weighing maximally underwater to residual volume hard with MR.</li> <li>Comparison of equations (In males 5 of 6 &amp; females 4 of 6, no significant difference</li> </ol>
1987 - Kelly & Rimmer	<ul> <li>170 males (aged 18 - 45 Used 2 studies 1 yrs);cognitive disability; validate derived 2 studies with 85 regression equa developed to pre participants each %BF in adult m</li> </ul>	<ul> <li>170 males (aged 18 - 45 Used 2 studies to cross- yrs);cognitive disability; validate derived</li> <li>2 studies with 85 regression equation developed to predict</li> <li>% BF in adult males w/MR</li> </ul>	height, weight, forearm & waist girth R	Obtained R values of 0.86 and 0.81 (SE = 3.13) on 2 studies.

Hydrostatic Kelly and Rimmer's (1987) derived weight equation exhibited highest without head reliability (r = 0.89); Recommended submerged. use for adult males w/ Downs	Compare results of 3Height,1) Females obese by all (30% BF)methods to measureWeight,BIA & II, no significant difference;%BF; Used generalizedSkinfoldSkinfold & girth significantly higher%BF; Used generalizedSkinfoldSkinfold & girth significantly higher%Dody density in mengirth; infrared uncooperative);(Inultiple) &(Jackson & Pollock, 1978)interactance;2) Males (20% BF); no significantwomen (Jackson, Pollock, bioelectricaldifference in 3 methods& Ward, 1980). %BF byimpedance3) Older females than malesSiri (1956) standard formulamight account for difference	Females with cognitive disabilities 1) exhibited lower muscle mass 2) higher percent body fat 3) lower pear force values for biceps & quadriceps strength 4) lower bone density but not significant
Hydrostatic weight without hea submerged.	Height, Weight, Skinfold (multiple) & girth; infrare interactance; bioelectrical impedance lla	DEXA
Determine accuracy of published regression equations published	age /rs; llas	<ul> <li>(14 MR mean Comparison study of /Down's premenopausal females</li> <li>8) on bone mineral density, body composition (% BF), &amp; muscle strength</li> </ul>
18 adult males; Down's syndrome	18 (M=9, F=9); Mean range 22.22 - 42.32 y Caucasians; Indep vi in Arizona; cognitive disabilities	16 females age 30; 2 w mean age 2
1991 - Ovalle, Cole, Climstein, & Dunn	1994 - Burkett, Lee, & Phillips	1998 - Felix, McCubbin, & Shaw

Hydrostatic total lung capacity procedures recommended by Weltman & Katch (1980) were utilized in the study. This procedure included expiring breath maximally underwater to residual volume, which is difficult for many persons with cognitive disabilities.

Researchers found no significant difference between the actual residual volume and a constant value of 1300 ml for the men and 1000 ml for the women (recommended by Wilmore, 1969) using a paired t-test. The constant value for participants (male and female) was added to the vital capacity measurement to obtain individual total lung capacity. Although no significant differences were found between 5 of 6 regression equation evaluations with men and 4 of 6 used with women, 3 equations had the greatest predictability. The following derived generalized regression equations were recommended for use in estimating the percentage of body fat in adults with cognitive disabilities: (a) for males, Durnin and Womersley (1974) (r = 0.84 and SE = 4.13) and Jackson and Pollock (1978) (r = 0.85 and SE = 3.95); and (b) for females, Jackson, Pollock, & Ward (1980) (r = 0.92).

## Kelly and Rimmer (1987)

Researchers developed a regression equation to estimate the percentage body fat in adult males (aged 18 to 40 years) with cognitive disabilities. The anthropometric measures used in the equation were height, weight, forearm and waist circumference. Two studies with 85, participants each (obtained R values 0.86 and 0.81, SE = 3.13),

were used to cross-validate the derived equation: %BF = 13.545 + 0.487 (waist circumference in cm) - 0.527 (forearm circumference in cm) - 0.155 (height in cm) + 0.077 (weight in kg).

Ovalle, Cole, Climstein, and Dunn (1991)

Researchers conducted a study with 18 adult males experiencing Down syndrome, to determine the accuracy of selected published regression equations. Hydrostatic weights were taken without head submerged. The researchers found Kelly and Rimmer's (1987) derived equation to exhibit the highest reliability (r = 0.89) and recommended its use with adult males having Down syndrome.

### Burkett and Phillips (1994)

Researchers compared the results of three methods for measuring percentage body fat in persons with cognitive disabilities (multiple skinfolds and circumference; infrared interactance; and bioelectrical impedance). There were 18 (9 male, 9 female) Caucasian participants in the study. Mean participant age range was 22.22 to 42.32 years (male  $26.22 \pm 4.02$ , female  $31.33 \pm 10.99$ ). Females had a mean height of  $62.11 \pm 2.71$  inches and mean weight of  $157.78 \pm 38.80$  pounds. Males had a mean height of  $67.33 \pm 3.12$  inches and a mean weight of  $143.22 \pm 26.64$  pounds. Participants lived in two independent villas (some on weekdays only) in Tempe, Arizona.

Measurements, including height and weight, were performed twice to determine body fat percentage using a combination of multiple

skinfolds and girth, bioelectrical impedance analyzer (BIA), and infrared interactance (II). BIA and II body fat percentages were calculated by machines using specific calibrations: (a) for BIA, sex, height, and weight were programmed into the machine analyzer; and (b) for II, age, weight, and activity level were calibrated into the Futrex 5000 body composition analyzer. Body fat percentages were arrived at differently for men and women using multiple skinfold and girth combinations, although both used Siri's (1956) formula to calculate the specific percentage: (a) for men, the sum of 3-skinfolds (chest, abdomen, and thigh) were used with 2-girth measures (forearm and waist) in the Jackson and Pollock (1978) generalized regression equations for body density; and (b) for women, the sum of 3-skinfolds (triceps, suprailiac, and thigh) and aged (instead of girth) were used with the Jackson, Pollock, and Ward (1980) regression formula to derive body density.

Results revealed females with cognitive disabilities tended to be obese; all 3 methods yielded a greater percentage of body fat for females (in excess of 30%) than males (mean was slightly over 20%). In this study, the greater mean age of females might account for some variance in body fat. Findings indicated no significant difference between the body fat percentages calculated by the three methods for males. The Burkett and Phillips (1994) study had excellent agreement with the Kelly, Rimmer and Ness (1986) investigation for males. For females, no significant difference was shown between the body fat percentages

calculated by infrared interactance and BIA. The results for females obtained with the combination of skinfolds and circumference (using the Jackson, Pollock, and Ward [1980] regression formula), were significantly higher than the other two methods. Although the researcher was trained to use Lange calipers, it was noted that errors in measurement could be magnified by uncooperative or obese participants (Litchford, 1987; Shaw, 1986; Wilmore and Behnke, 1970). Researchers emphasized the importance of early weight control intervention, and need for continued research to find an accurate method for calculating percentage body fat in individuals with cognitive disabilities.

# Felix, McCubbin, and Shaw (1998)

Researchers compared bone mineral density, body composition, and muscle strength in premenopausal females with cognitive disabilities  $(n=16, mean age 28.14 \pm 8.43 \text{ SD}, 2 \text{ with Down syndrome})$  and without  $(n=14, mean age 29.64 \pm 10.86 \text{ SD})$ . Many females with cognitive disabilities are known to exhibit low levels of activity, muscle strength, and muscle mass, placing them at increased risk for developing osteoporosis, which could affect level of weight and health-related fitness prior to age 20. DEXA was used to measure body composition and bone density (for osteoporosis) in this study. No other studies were located in literature that used DEXA, for any reason, with individuals experiencing cognitive disabilities; there were no difficulties or ill effects caused by this procedure. Females with cognitive disabilities exhibited: (a) lower muscle

mass  $[39.87 \pm 5.85 \text{ vs. } 47.18 \pm 4.00 \text{ kg}]$ ; (b) higher percent body fat  $[31.88 \pm 8.74 \text{ vs. } 26.03 \pm 4.01\%]$ ; (c) lower force values for biceps  $[8.33 \pm 2.30 \text{ vs. } 15.13 \pm 3.92 \text{ kg}]$  and quadriceps strength  $[25.65 \pm 9.49 \text{ vs.} 55.78 \pm 11.90 \text{ kg}]$ ; and (d) lower bone density, but not statistically significant, when compared to the persons without disability. *Himes (2001)* 

The researcher reviewed U.S. NHANES III data, epidemological data collected from 1988 to 1994 by the NCHS, frequently utilized in studies of overweight and obese people. Government researchers conducting this survey included a greater than skinfold caliper (GTC) category for individuals having one or more skinfold thickness too large (over 50mm) to be measured by their calipers (Holtain). Four skinfold sites were measured in NHANES III (triceps, subscapular, suprailiac, and anterior thigh). The most frequent site too large in be measured in males was the suprailiac (65.3%), and thigh (89.8%) in women. Individuals with the largest, unmeasured skinfold thicknesses were coded to the GTC group, and could not be accurately reflected in data reported. The GTC group included 15.3% (males = 2.5%, females = 12.8%) of the U.S. population surveyed (over age 2, not institutionalized), and 7.2% of non-Hispanic white persons. Among the NHANES III findings reported for the GTC, nearly one-quarter of women 50 and older had at least one measurement too large for Holtain calipers. Persons in this category tended to be older than the general population (42 years rather than

34.1), with no difference in poverty to income ratio. Individuals in the GTC category had higher BMI mean (35.6 versus 26.6 kg/m<sup>2</sup>) and skinfold median more than twice that of the general population. Missing measurements and GTC information reported impacts the usefulness of NHANES III results; prevalence estimates, means, and upper skinfold thickness percentiles could not be correct.

# Horodyski (2003)

The researcher compared the percentage of body fat estimated for 21 female collegiate swimmers (mean age 18.5) by: (a) dual energy x-ray absorption [DEXA] [mean 20.93]; (b) sum of five skinfold sites (abdomen, subscapular, suprailium, thigh, and triceps regions) (mean 22.99); and (c) sum of six skinfold sites (chest, abdomen, subscapular, suprailium, thigh, and triceps regions) (mean 16.78). Paired t-tests (level of significance p < .05) revealed that significant differences were found between DEXA and the other procedures. When the accepted  $\pm$  3% error range was considered, the difference between DEXA and sum of five skinfolds procedure was not significant. Horodyski recommended that the sum of five skinfolds procedure be used with persons not having disabilities when DEXA is not available. This finding may be true for individuals with disabilities as well.

# Summary of Literature Reviewed

The majority of studies reviewed (Appendix D), revealed the high prevalence of overweight and obesity, and examined the effectiveness of

short-term weight loss programs for individuals with cognitive disabilities. Summaries of literature reviewed were included at the end of each topic. Experimental research designs lacked uniformity and description. Criterion that designated individuals as overweight or obese were inconsistent among studies of individuals with cognitive disabilities.

Few studies for this population considered change in body composition, the component of health-related fitness most closely associated with physical wellness. A paucity of researched interventions included the well known combination of activity and nutrition to control weight and possibly improve health of persons with cognitive disabilities. Future body size research for individuals with cognitive disabilities should be mindful of *GAP* goals and focused on health-related fitness. Controlled experimental designs should include interventions of exercise and nutrition, and rigorous statistical examination to avoid methodological biases and facilitate comparisons.

#### CHAPTER 3: METHODOLOGY

# Overview

The purpose of this study was to determine and describe the effects of a 12-week program of basic nutrition and health instruction combined with exercise training, on adolescents and young adults with moderate cognitive disabilities. The specific parameters of the study investigated were the intervention's effect on body composition, weight, and perceptions. Prior to initiating this study, approval was obtained from the University of Oklahoma's Institutional Review Board (Appendix E). All procedures were conducted in accordance with the guidelines for ethical treatment of human subjects.

# **Research Questions**

The specific research questions in this study were:

- Will a program of exercise and basic nutrition and health education have an effect on the body composition of adolescents and young adults with moderate cognitive disabilities?
- 2. Will a program of exercise and basic nutrition and health education have an effect on the body weight of adolescents and young adults with moderate cognitive disabilities?
- 3. Will a correlation exist between field methods selected to estimate body composition in participants?
- 4. Will a program of exercise, basic nutrition, and health education have an effect on the knowledge of these concepts in adolescents and

young adults with moderate cognitive disabilities?

5. From the perspective of participants and their parents, did a program of exercise and basic nutrition and health education have an effect on them?

# Research Design

This study utilized a mixed-methods design, including elements of qualitative, quantitative and small group (applied behavior) approaches (Tashakkori & Teddlie, 1998). The quantitative comparison study included a matched control group. Qualitative measures of parent and participant self-perceptions were included. Repeated measurements (pre- and post-) were collected and compared on dependent variables of interest to determine the effects of the intervention program. Additional information was gleaned from multiple sources (such as interviews, questionnaires, researcher observations, field notes, and unique participant archived data) for triangulation. Strengths of mixed-method research designs include: (a) reduction of limitations and biases that might be present when an individual method is used; (b) possibility of new questions arising from the variety of data collected and analysis that might increase understanding of the research topic; and (c) addresses problems often inherent in studies with small samples (such as statistical power and confidence level) (Berkson, Andriacchi, & Sherman, 2001; Creswell, 2003).

#### Research Setting

Data collection occurred in two community venues that provided opportunities for contact with individuals not experiencing disabilities. A community church's recreation building that included a gymnasium with full-size basketball court, meeting rooms, and kitchen was utilized. Weekly sessions were sandwiched between middle school volleyball team practices and Boy Scout meetings. The second venue utilized weekly was a two-story athletic club with an exercise equipment area, exercise rooms, and flights of stairs between floors. The venues offered opportunities for generalization of exercise training across settings in comfortable, air-conditioned surroundings that provided adequate space for movement and equipment appropriate to this study (McDonncha, Watson, McSweeney, & O'Donovan, 1999). Participant questionnaires, interviews, and basic concept instruction and training were conducted in exercise and training facilities. Parent interviews took place in quiet, comfortable environments that were free from distractions (usually homes or meeting rooms).

# Participants

The purposive convenience sample included 18 (7 females and 11 males) volunteer adolescents and young adults with moderate cognitive disabilities, as defined by the American Psychological Association's DSM-IV-TR manual (American Psychological Association, 2000). Individuals taking part in the study did not receive monetary payment or gifts.

Confounding variables were reduced by the similarity of sample characteristics, which provided the opportunity for matched groups.

- Living arrangements were approximately the same. All participants lived with their parents in the suburbs of a large south-central United States metropolitan community.
- 2. Cognitive abilities of sample members were approximately the same. All individuals possessed the primary diagnosis of MR. Etiologies were varied and included syndromes (Asperger, Down, Prader-Willi, and fragile X), specific clinical diagnosis (cerebral palsy), and MR of unknown origin. Functional ability levels varied slightly.
- Physical abilities of sample members were approximately the same.
   All participants were verbal, able to follow directions, ambulatory, and were non-smokers.
- 4. The educational opportunities for sample members were essentially the same. All persons had been involved in special education programs, 15 from the same public school district, one from a neighboring district, and two were home schooled using a cooperative system.
- 5. Sample members were recruited from the same unique, intact 10year old community group for adolescents and young adults with cognitive disabilities. All participants had been involved with this group between 4 and 10 years.
- 6. Activity options for sample members were approximately the same.

- 7. All sample members were familiar with seasonal, rigorous, structured swim training.
- 8. Sample members were required to maintain current Special Olympics physicals on file that included physician approval to take part in vigorous activities (Appendix F).

The sample was randomly assigned to two groups: intervention participant group (referred to as *participants*) and control group. The participant group was comprised of 11 individuals (4 females and 7 males) ranging in age from 14 to 31 years (mean 21). Seven individuals (3 females and 4 males) ranging in age from 15 to 23 years (mean 19), were members of the control group. The groups originally formed were more equal in size; three individuals were dropped from the control group when they were unable to attend pre-intervention weigh-in sessions.

The individuals in the study groups were matched on subject variables and the only essential difference between them, for the specified period, was the addition of the intervention to the participants' schedules. The purpose of using the control group was to determine and compare any weight and BMI changes that occurred following the sample's normal routine, without intervention, with any changes that might be achieved by adding exercise training and basic health and nutrition information. At least one parent of each participant took part in an interview related to their perceptions of the health-related fitness of their offspring.

The sample was recruited from a nonprofit status organization that was organized by the family of a child with cognitive disabilities. It was originally formed to provide a team atmosphere (coaches and uniforms), sponsorship avenue, and a system to train a limited number of adolescent and young adult swimmers with moderate cognitive disabilities to compete in Special Olympic venues not sponsored by their schools. To enable safe, quality stroke instruction in rented public pools, with a ratio of no more than one coach to five swimmers, the team size was capped at 20. The organization supported many individuals who would otherwise not have been able to take part in the vigorous sport of swimming as part of a team. The group maintains a waiting list to fill the few empty slots that become available through attrition.

Typical fan support was added, similar to that provided in extracurricular activities for adolescents without disabilities. The organization supported arrangements for social and recreational gatherings, sports competitions, and member educational programs. The team hosts an annual cross-city swim meet for a sister team they organized 7 years ago. Current, the organization sponsors these individuals in several Special Olympics team and unified venues (golf, bocce, horseshoes, basketball, bowling, fine arts, and swimming).

The number of team members with cognitive disabilities and their families involved in team related activities, other than swimming, has grown. Efforts of active member families have provided opportunities for

additional individuals with cognitive disabilities to take part in planned activities such as art and dance classes, cooking, weekly bowling, seasonal basketball, walking and jogging training for a city marathon, academics, diversity foundation, and church choir. Plans for assisted high-rise apartments and employment opportunities have grown from the original group. Parents have been provided classes on various topics from the legal aspects of special education to sports safety. Consultation and support for individualized education plan meetings, and subject modification has also been available through this organization.

# Data Sources

The pragmatic, 3-prong mixed-methods, quasi-experimental research design provided an avenue to collect data from multiple sources to evaluate and describe the effects of the intervention used in this study (Table 17). Perspectives of participants and their parents were included to provide greater depth than gained from pure numbers alone, and social context for the data.

# Measures

The difference in mean body composition for participants was determined by comparison of repeated measures on dependent variables. Baselines were established for variables from pre-intervention measurements. Methods to estimate body composition, including percentage of body fat, were selected from the wide range of techniques located in the literature. In-vivo functional measurement techniques

DATA SOURCES: MEASURES AND ANALYSIS	<b>ZES AND ANALYSIS</b>		
Inquiry Method	What Measured	How Measured	Analysis of Change
<u>Quantitative (DV)</u> (Dependent Variables -pre & -post measures)	Body Composition Body Mass Index	Weight, height calculation (W/H²) Online calculation (CDC) Skinfold Thicknesses	ANOVA (2 x 3) t-test t-test t-test
	Relationship of measures	Includes above measures plus single measurements on nomogram and standardized chart	Correlation reliability of measure
	Body Fat Percentage	Regression Equations	t-test
	Total Inches	Circumference (girths added)	t-test
	Basic Concept Knowledge	Paper-pencil test	t-test
Single Subject	Weight Change	Pounds	AB graph with probe
Qualitative	Perceptions of participants, parents, and researcher	Semi-structured interviews; Field Notes; Archival data (permanent paper products)	Textual Triangulation

Table 17

must be easily performed, widely available, inexpensive, valid, reliable, and facilitate evaluation. The most valid techniques are probably not commonly used in field studies with individuals having cognitive disabilities; reference values are not widely available (Cronk & Roche, 1982). Comparisons of pre- and post- measurements were made to determine the effects of the intervention. Table 18 provides an overview of field body composition measures.

Body composition. This variable was selected because it reflects the portion of components (lean and fat masses) that make up the body's weight. Percentage of body fat is considered a more accurate indication of health and wellness than body weight (CDC, 2004; Insel & Roth, 2004). Laboratory body density measurements that directly measure body fat, were not included in this study because they were expensive, difficult to obtain, and IRB approval could not be obtained. Repeated measures of height, weight, and skinfold were used to estimate body fat and body size and were compared to determine the effects of the intervention. Estimates of body fat were derived from the methods located in the literature (Table 18). Body measurements were performed in standard American units (feet, inches, and pounds) and converted to metrics when necessary to conform to accepted formulas. The most frequently used technique to estimate body fat in the literature was Quetelet's metric formula (known as BMI), weight in kilograms divided by height (stature) in meters squared ( $W[kg]/S[m]^2$ ) (Garrow & Webster,

FIELD METHODS TO ESTIMATE BODY COMPOSITION FROM LITERATURE	
1. Body Mass Index (BMI) - Calculation from anthropometric measures a. Height - weight calculations	Quetelet's Index, called BMI, most widely accepted
<ul> <li>(1) weight in kilograms divided by height in meters squared</li> <li>(W[kg]/H[m]<sup>2</sup>), also noted as W/S<sup>2</sup> (best simple %BF &amp; TBF for men &amp; TBF in women)</li> </ul>	Cronk & Roche, 1982; Garrow, Webster, 1985; Keys, Fidanza, Karvonen, Kimura & Taylor (1972)
b. Online interactive calculator (CDC website, 2004), fill-in height & weight (American or metric measures)	Anderson & Jakicic (2003); CDC, (2004)
c. Standardized height and weight tables (NIH/NHLBI; CDC) d. Nomograms (chart with 2 factors intersecting at % RF)	CDC, 2004; Khosla & Lowe (1967)
<u> </u>	Roche, Siervogel, Chumlea, & Webb (1981) Chessher, M. (1999)
<ol> <li>2. Skinfold thickness to estimate %BF         <ul> <li>a. Triceps only (for boys and females of all ages)</li> <li>b. Subscapular only (for TBF in boys)</li> <li>c. and females of all ages)</li> </ul> </li> </ol>	Fox, Burkhart, & Rotatori (1982) Cronk & Rocke (1982); Katch & Katch, 1980 Cronk & Rocke (1982)
<ul> <li>c. Sum of two site regions</li> <li>(1) triceps and calf</li> <li>(2) triceps and subscapular</li> <li>c. Sum of four site regions (biceps, triceps, subscapular, suprailiac)</li> <li>e. Sum of five site regions</li> <li>f. Sum of six site regions</li> </ul>	Pi-Sunyer, 1994 Pi-Sunyer, 1994 Durmin & Womersley, 1974
3. Total inches (sum of circumference measures [such as waist and hip])	Bray, 1987
<ol> <li>Combined skinfolds and girth measurements         <ul> <li>Men - 3 Skinfolds (chest, abdomen, &amp; thigh) + Girth (forearm &amp; waist)</li> <li>Women- 3 Skinfolds (triceps, suprailiac, &amp; thigh) + Age (not girth)</li> </ul> </li> </ol>	Rimmer, Kelly, & Rosentswieg, 1967 Jackson & Pollack, 1978 Pollack & Ward, 1980
5. Regression equations (compared to hydrostatic weighing & DEXA)	Durnin & Womersley, 1974; Horodyski, 2003; Siri, 1956;
Note: Different measures of body fat include percentage of body fat (%BF) and total body fat (TBF) and they may vary in their health- related significance (Cronk, & Rocke, 1982).	otal body fat (TBF) and they may vary in their health-

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Table 18

1984). This method, used by NHANES to estimate BMI is considered a reliable indicator of overall health for both genders (NCHS, 1971, 1994; NHLBI, 1998a, 1998b, 1998c, 1998d, 2004; WHO, 1995). BMI and waist girth are used as screening tools for identifying persons that are at possible risk for developing chronic diseases (CDC, 2004; NHLBI, 2004). The use of minimal anthropometric measurements to estimate body fat were located in the literature and found valid, with SE  $\pm$  3.0 considered an acceptable variance (Cronk & Roche, 1982; Guo, Roche, Chumlea, Gardner, & Siervogel, 1999; Roche, Siervogel, Chumlea, & Webb, 1981). An example is the suggested use of triceps skinfold thickness (males and females of all ages) and W/S<sup>2</sup> (males) (Cronk & Roche) as the best simple indicators of percentage body fat. Possible correlation between the results, obtained by various methods used in this study, was examined.

*Total inches.* Girth measurements were used to assess body fat distribution. Total inches (the sum of combined circumference measurements) were used by certified personal fitness trainers to measure the effects of exercise on body tone.

Weight. Means of repeated weight measurements (pre- and post-) for each group were compared. As an awareness tool, participants used ABA graphs (A-B design with probes across time design), with the help of researcher and assistants, to record their weights. The researcher selected this variable to make comparisons to research studies in the literature, because it was known by participants, and is a widely used

gauge of body mass.

*Basic concept knowledge.* Repeated measurements (pre- and post-) of paper-pencil questions, designed to assess participants' knowledge of basic nutrition and health concepts, were compared. Researcher and assistants provided assistance recording answers, if needed. Researcher observation and anecdotal field memos indicated in-class response data. *Perceptions* 

Participants and their parents provided information through qualitative semi-structured interviews, permanent paper products (such as food and activity logs), and archived data. Researcher's perceptions were developed through observation, field notes, and archived data (such medical records). Member checking occurred after each interview was transcribed, to ensure accuracy of information recorded. Establishing reliability and validity for data collected qualitatively, also known as trustworthiness, was difficult. Creswell (1998) suggested that researchers use a minimum of two of the listed eight verification procedures: (a) prolonged engagement and persistent observation; (b) triangulation; (c) peer review or debriefing; (d) negative case analysis; (e) clarifying researcher bias; (f) member checks; (g) thick, rich description; and (h) external audits. The current study included (a) prolonged engagement and persistent observation, the researcher had worked with participants for 4 to 10 years and noticed the effects of the intervention; (b) triangulation [parallel analysis]; (c) multiple input sources [interviews,

discussions, permanent paper products, archived data]; (d) member checking (self-reviewed interview transcripts) and; (e) thick, rich description (participants' perceptions summarized and words quoted). *Instruments* 

Assessment of participants' prior knowledge of basic nutrition and health concepts, eating habits, and exercise patterns was necessary prior to the application of the intervention. Researcher-created instruments were utilized to collect data in this study (Appendix G).

Average daily food intake. This pre-intervention instrument was completed by participants and their parent proxies, prior to instruction, during the first education session. In order to increase awareness of their eating behaviors, they described eating habits for meals and snacks, and indicated food preferences. Participants and their parents also shared how frequently they dined at restaurant and fast food establishments, and named their favorites.

Participant pre-study questionnaire. This 10-question protocol was developed to gather general attitudes toward exercise and nutrition. The form asked about the types of activities individual participants were involved in, or would like to try. The form gathered information about self-determined weight concerns or body toning issues that individual participants wanted to address through the study's intervention.

*Participant post-study questionnaire.* This 9-question protocol was used to gather data after the intervention was completed.

Food and activity log. Participants, assisted by their parents, recorded daily food intake, activities (alone or with someone else), and pedometer steps taken for one week. This activity was to done to enhance their awareness of individual activity and eating behaviors.

Paper-pencil knowledge assessment. Paper-pencil assessments were utilized to evaluate knowledge of basic nutrition and health concepts prior to intervention. The researcher and research assistants administered the one-on-one assessments (a few questions at a time) prior to beginning instructional periods. The questionnaire was adapted from the Haring and Sawey (1984) study. Basic nutrition concepts included knowledge of calories, food portions, food types and components (fats, protein, and carbohydrates), food groups, and weight maintenance. Basic health concepts included temperature, muscle groups and the effects of exercise, cardiovascular and digestive systems, weight, and body composition.

Parent perception interview protocol. A 7-question semi-structured interview form (Appendix H) was used to obtain information concerning health and activity issues. This interview format allows additional information to be gathered through open-ended questions and probes.

# Apparatus and Materials

# Research Protocol

*Nutrition and health education.* An appropriate nutrition, health, and exercise curriculum for individuals with moderate cognitive

disabilities did not exist. Therefore, the researcher developed a curriculum that included, but was not limited to: (a) basic concepts with examples and fun facts; (b) basic anatomy, including muscle groups; (c) exercise pyramid scope and sequence; (d) food pyramid, groups, and substitutions; (e) meal and snack plans; and (f) food nutrient content. Multiple methods (such as hands-on activities and visual materials) were used by the researcher to provide instruction in basic health and nutrition concepts.

Snack and food demonstrations and hands-on activities were conducted in the kitchen of the church recreation building periodically, in consultation with a dietician. Color choice cards were presented during group instruction to give participants opportunities to make choices regarding nutrition and exercise. Models and activities were used to demonstrate health and exercise concepts.

Participants developed weight goals and were instructed in the use of graphs to track their progress. Total inches were also indicated on graphs. Parents were provided information on basic nutrition and health concepts. Individual *Healthy Choice* notebooks were provided to each participant after concepts were introduced, to collect and store supplemental materials (such as handouts, graph paper, and exercise cards). Sample information is provided in Appendix I.

*Exercise training protocol.* A structured exercise regime, including warm-up and cool-down activities, was delivered by certified personal

fitness trainers in accordance with current physical activity recommendations (Table 19) by experts in the fields of physical education and health (ACSM, 1998; Barlow & Dietz, 1998; CDC, 2004; Insel & Roth, 2004; Pate, 1995; Pate, Pratt, & Blair et al., 1995; Simons-Morton, Parcel, O'Hara, Blair, & Pate, 1988). Appendix J provides a sample workout.

### Equipment

*Exercise equipment.* Training equipment utilized in the gym and health club included: (a) 1-inch roll-up exercise mats [padded, covered one inch foam]; and (b) hand dumbbell weights [1 to 10 pounds each, hex or neoprene coated], used for strength training and resistance exercises. Equipment used only at the all-purpose gymnasium complex included jump ropes and basketballs. Equipment used solely at the exercise club included recumbent bicycles and exercise steps.

Measurement equipment. A portable Precision Tech Professional scale (model 905), accurate to 400 pounds, with raised dial, and ProHelix rack and pinion (manufactured by Taylor Precision Products/Metro Corporation, Las Cruces, New Mexico) was used to measure all weights during the study. This scale was selected because its portability allowed use at multiple locations. Weight measurements were easy to see and quickly obtainable from the over-sized digital display. Weighing on the scale provided an opportunity for participants to practice a lifetime health skill.

Table 19	
Exercise Recommendations For Healthy Adults	ns For Healthy Adults
	<u>Exercise to Develop and Maintain Cardiorespiratory Endurance and Body Composition</u>
Frequency of Exercise:	3-5 days per week.
Duration of Exercise:	<ul> <li>Aerobic activity: 20-60 total minutes of continuous or intermittent (in sessions of 10 minutes or more.</li> <li>Duration is dependent on the intensity of activity:<ol> <li>Conduct lower-intensity activity over a longer period of time (30 minutes or more).</li> <li>For non-athletic adult, lower-to-moderate intensity activity of longer duration is recommended.</li> </ol> </li> </ul>
Intensity of Exercise:	<i>55/65-90%</i> of maximum heart rate or 40/50—85% of maximum oxygen uptake reserve. Average fitness: Intensities of 70-85% of maximum heart rate are appropriate. Low fitness: Lower value (55-64% maximum heart rate and 40-49% maximum oxygen uptake reserve).
Type Activity:	Any activity that uses large-muscle groups, can be maintained continuously, and is rhythmical and aerobic in nature. Examples: walking-hiking, running-jogging, cycling- bicycling, cross-country skiing, aerobic dance, and other forms of group exercise, skipping rope, rowing, stair-climbing, swimming, skating, and endurance game activities.
Exercise	Exercise to Develop and Maintain Muscular Strength and Endurance, Flexibility, and Body Composition
Resistance training	One set of 8-10 exercises that condition the major muscle groups should be performed 2-3 days per week. Average fitness: Complete 8—12 repetitions of each exercise. Less fit: Complete 10—15 repetitions with a lighter weight. Multiple-set regimens may provide greater benefits if time allows.
Flexibility Training Str we	Stretches for the major muscle groups should be performed a minimum of 2—3 days per week; at least four repetitions, held for 10—30 seconds, should be completed.
Note: Adapted from the Am developing arid maintainin 30(6), 975—991.	Note: Adapted from the American College of Sports Medicine. 1998 ACSM position stand. The recommended quantity and quality of exercise for developing arid maintaining cardiorespiratory and muscular fitness and flexibility in healthy adults. Medicine and Science in Sports and Exercise 30(6), 975–991.

Lange calipers (which applied the recommended constant 10 grams per square millimeter pressure) were used to perform skinfold thickness measurements. Skinfolds up to 63 cm could be measured with this caliper.

Participants wore pedometers that automatically measured steps walked or jogged for a week prior to initiating the intervention. Findings were self-reported on food and activity logs with parent proxy assistance, if needed. The purpose of the activity was to gain awareness of current activity levels. Participants were issued either the Accusplit Eagle 170 Deluxe Fitness Meter (with calorie counter and leash feature, costing \$39 per unit, 2 issued) or the less expensive Sportline Electronic Pedometer 330 (approximately \$5.99 per unit, 9 issued).

Reference tables for estimating body composition. Lean and fat masses were estimated by the primary certified personal fitness trainer from ACSM (1995) standardized tables. These tables were normed on the general population and based on height, age, gender, and skinfolds. Trainers obtained the tables during their certification process, and used them for all clients.

The researcher reviewed and compared a variety of methods to derive body fat percentage estimates. Validated tables and nomograms have not been developed for persons with cognitive disabilities. BMI estimates were obtained from standardized weight for height tables and charts normed on the general population (United Health Foundation,

2000). Height and weight based BMIs were also derived using Quetelet's W/S<sup>2</sup> metric formula and CDC's online calculator (metric and American scales are available) (CDC, 2004; Garrow & Webster, 1984; NCCDPHP, 2003; NHLBI, 2004).

The 1959 Metropolitan Life Insurance ideal weight for height table with bone structure options was considered but not used in this study. A nomogram developed by the University of Texas (Chessher, M., 1999) and skinfold thickness reference charts (ACSM, 1995) were also used to estimate body composition. Body fat percentages obtained were applied to a table that screens for the risk of developing obesity-associated diseases (CDC, 2004; NHLBI; 2004).

#### Data Collection Procedures

# Recruitment

Recruitment notices were sent to members of a community organization for individuals with cognitive disabilities. A group meeting for potential participants and their parent advocates was held to fully explain and answer questions about the 12-week program (Cluphf, O'Connor, & Vanin, 2001; Insel & Roth, 2004). Volunteers signed the applicable study forms. Participants and their parents did not receive monetary or gift payments to take part in this study. Appendix K contains the University of Oklahoma IRB approved recruitment notice, photography release, and assent/consent forms. Current physical examination reports were supplied to the researcher.

Random assignment to groups was made at the end of the recruitment meeting, according to research design. The control group was not wait-listed because prior researchers thought it lead to weight gain (Rotatori & Fox, 1980; Rotatori, Fox, Matson et al., 1986; Rotatori, Fox, & Switzky, 1980). The control group continued their normal activities and agreed to have their heights and weights measured preand post-intervention. Intervention participants agreed to: (a) spend a minimum of three hours per week doing vigorous physical activity for the duration of the study (a minimum of two weekly one-hour researcher directed sessions and an additional hour in a self-reported physical activity of their choosing); (b) take part in weekly instructional sessions on basic nutrition and health topics; (c) fill out a food and activity log; (d) wear a pedometer for one week, before and after, the intervention; (e) have several measurements taken; and (f) participate in answering survey and interview questions. Parents of the participants also voluntarily agreed to take part in researcher directed interviews. Pre-Intervention

Awareness activities conducted and baseline measurements that occurred prior to introducing the intervention are described.

*Baseline*. Initial measurements for dependent variable (DV) baselines (Table 17) were performed by the primary certified personal fitness trainer after the information and signature session ended. ABA guidelines of performing measurements until stable or at least twice to

establish baselines were followed (Richards, Taylor, Ramasamy, & Richards, 1999). The second measurements were taken two days later, and the third was performed on the first night of intervention, prior to exercise.

Participant awareness of change. Individual participant's baseline weights were charted on A-B graphs constructed on white bond graph paper with blue-inked one-quarter inch squares for ease of use and visibility. Graphs were placed in individual notebooks with goals indicated, if applicable. Self-monitored progress was encouraged with probes and post-intervention weights. Pre- and post- total inches and skinfolds were included on graph sheets for participant comparison.

Self-identified body size concern. In order to determine if persons in the participant group had self-identified weight or body-toning issues, the researcher asked three questions in addition to the pre-intervention surveys: (a) What do you think of your body shape? (b) Do you like your body weight? (c) Do you have any physical fitness goals? Categorical replies and anecdotal comments were recorded. Study participation was not linked to replies.

Research personnel training. Two personal fitness trainers took part in this study. Both were certified (American Federation of Fitness Associates [AFFA] or National Fitness Professional Association [NFPA]). Trainers followed the same sequence and pattern of exercises used with other clients. The primary trainer, a study consultant, was acquainted

with one participant prior to beginning the intervention. No special instruction on working with participants was needed.

A dietician-nutritionist, with a master's degree in special education, acquainted with all participants, was a consultant and took part in planning and preparing healthy snacks. Two research assistants, with a minimum of four years experience with participants, received instruction in the study's general research protocol. They provided supervision and assistance during exercise workouts and, in initially unfamiliar surroundings, pointed-out restrooms, water fountains, and towel bins.

The researcher and an assistant provided interrater reliability data when measurement data was collected, assisted with graphs, provided observational information (social interactions, exercise difficulties), and assisted during paper-pencil assessments (Baumgart, Filler, & Askvig, 1991). Two parents, that had been well acquainted with all participants for a minimum of five years, and research assistants were trained to serve as proxies when qualitative information was gathered and discussions ensued (Agnes & Guralnik, 2001).

Anthropometric measurement. Participants wore lightweight exercise clothing and were in sock feet when measurements were performed. The mean of two measurements was recorded for each participant, for each occurrence. Pre- and post-intervention measurements were performed for all dependent variables with an

interrater observer present 100% of the time. Interrater agreement achieved was 96%. To establish reliability in measurement methods and validity of comparisons, the same primary certified personal fitness trainer and research assistant performed all anthropometric measurements. The same scales, calipers, and tape measure were used for all measurements. The study included the same participants.

Height measurements were recorded to the nearest one-half inch and performed on a wall-mounted measure. American units were converted to metrics, for use with Quetelet's BMI formula, by dividing height in inches by 39.37 (Barrow, McGee, & Tritschler, 1989). Repeated measures (pre- and post-) of height were performed to control the possibility of adolescent or young adult participant growth that could affect BMI. Height measurements were used in BMI formulas and with standardized tables, charts, and nomograms. Accurate long-term longitudinal follow-up was possible using a height/weight ratio to counter balance the effects of maturation on adolescents.

Weights to the nearest one-quarter pound were taken for each participant on three occasions. A probe was taken and posted on participant's individual graphs during the study, at follow-up, and maintenance. American measurements were converted to metrics, for use with Quetelet's BMI formula, by dividing the mean pound weights by 2.2 (Barrow, McGee, & Tritschler, 1989).

The thickness of a double fold of skin and adipose tissue was

measured using the Lange caliper to determine participants' degree of body fatness in a minimum of three areas (triceps, calf, subscapular) (Barrow, McGee, & Tritschler, 1989; Jackson & Pollack, 1985). Repeated measures (pre- and post-intervention) were performed following accepted procedures. Triceps skinfold thickness measurements were taken on the back of the right arm over the triceps muscle, midway between the elbow and the shoulder. Participants were instructed to stand erect, with arms relaxed, and palms facing their legs. The trainer grasped and gently lifted a vertical skinfold between the thumb and index finger, placed onehalf inch above the midpoint of the upper arm. The caliper measurements were taken at the midpoint of the upper arm. Calf skinfold measurements were taken on the inside (medial) of the right leg at the largest part of the calf girth. Participants stood with the right foot on a bench with the knee slightly flexed. The trainer grasped and gently lifted a vertical skinfold between the thumb and index finger, one-half inch above the measurement site. Subscapular skinfold measurements were taken on the right side of the body. The scapula protruded when the arm was gently placed behind the back. The trainer grasped and gently lifted a vertical skinfold one-half inch below the inferior angle of the scapula, in line with the natural cleavage of the skin. Additional skinfold measurements were performed on selected participants by the trainer (thigh, pectoral, and abdomen), according to prescribed procedures.

Body circumference (girth) measurements were taken with a paper tape measure that would not stretch, according to guidelines. All participants were measured in a minimum of three sites (waist, upper arm, chest [males only], and thigh). The trainer performed additional girth measurements (calf, forearm, hip, shoulder) on selected participants for use in generalized regression equations.

Knowledge of basic nutrition and health concepts. Prior background knowledge of nutrition and health concepts to be presented was assessed using the instrument developed for this intervention. Repeated paperpencil assessments were conducted pre-introduction of new material at weekly instructional sessions and post-intervention. To avoid reading ability as a confounding variable, questions were read to participants and their proxies individually by the researcher or assistants. If needed, proxies assisted participants in marking their replies. Each assessment occurrence was short, with five or fewer questions administered in a light, non-threatening manner. The total number of correct answers preand post-intervention were compared to provide an indication of change in knowledge of basic nutrition and health concepts retained during the intervention.

# Perceptions of Participants and Parents

Participant and parent perceptions were obtained through semistructured interview questionnaires and memoed discussions with the researcher during training and instruction sessions. Permanent paper

products (such as physical examination reports, individual graphs, selfreported food and activity logs, daily average food intake, and preintervention questionnaires) played a role in forming perceptions of health-related fitness and effects of the intervention. The researcher gleaned information from multiple sources including these, archived historical information, observation, and field notes.

# Intervention

A combined intervention of healthy nutrition concept instruction and regular vigorous health-related fitness (Table 20) exercise training was introduced (referred to as Healthy Choice). The objective of the intervention was to increase participant knowledge of health related concepts and change body composition (such as muscle mass).

Participants met twice weekly (for 12 weeks) with the researcher and certified personal fitness trainer for 1 to 1½ hours per session. They also took part in a weekly, self-reported third hour of self-determined physical activity for the duration of the intervention. Participants were known to walk for exercise and take part in seasonal physical activities (such as team swimming and basketball practices, marathon training, golf, skating, bowling, bocce, golf, and horseshoes). Individuals still attending school took PE classes (adaptive and general curricular), if their schedules allowed.

Participants signed-in at the beginning of bi-weekly sessions to establish structure and monitor attendance. The researcher provided

Table 20		
Exercises For Major Compone	Exercises For Major Components of Fitness Most Related to Health	
Component	Description	<b>Exercise Activity</b>
1) muscular strength	maximum amount of force a muscle or group of muscles can generate with single maximum effort	weights, body resistance, calisthenic exercises: sít-ups, push-ups
2) muscular endurance	ability to avoid fatigue with level of muscle tension	like muscular strength, stress muscles with greater load than used to; intensity, repetition
3) cardiovascular endurance	ability to perform prolonged, large muscle, dynamic exercise at moderate to high levels of intensity	continuous rhythmic movement of large muscle groups, aerobic dance
4) body composition	indication of the degree of fat to fat-free mass (muscle, bone, and water), or leanness to fatness of the body	lose fat through a lifestyle that includes sensible diet & exercise; add muscle mass with weights and resistance training
5) flexibility	ability to move joints through full range of motion	stretching

instruction in basic health (including the effects of exercise) and nutrition concepts, once a week (Thursdays from 5:30 to 7 p.m.) in the gymnasium or adjoining kitchen. The educational component preceded the exercise and recreation activities, with healthy snacks or drinks at the end. A dietician consultant was periodically present during healthy snack preparation.

The primary certified personal fitness trainer provided exercise training in all areas associated with health-related fitness. Exercise equipment included hand weights, step-benches, recumbent bikes, jump ropes, and exercise mats. The primary trainer worked with the participants at the church gymnasium on its full-size basketball court. An additional trainer joined the group at the health club (Sundays from 4:30 to 5:45 p.m.) for upstairs warm-ups on recumbent bicycles and downstairs exercise bout, consisting of floor and step exercises, with resistant weight training in large exercise classrooms.

Pre-intervention measurements and assessments needed were conducted at the beginning of the first meeting (such as average daily food intake sheet, mealtime habits, and favorite places to dine out). The Healthy Choice intervention began by introducing participants and proxies to the trainer and session sequence for the following weeks. The importance of drinking water and making good nutritional and activity choices, and was mentioned during all sessions. To embed the practice of water replacement during exercise, participants were

encouraged to bring water bottles to biweekly exercise sessions. Tightly booked space at the gym and health club taught participants the importance of following a time schedule, watching the clock, and taking turns. Time permitting, recreational basketball hoop shooting followed exercise sessions. A brief topic and sequence description of the Healthy Choice intervention program implemented (combined exercise training and basic health and nutrition instruction) is provided in Table 21.

Week 1: The basic concepts of how the body (muscles and bones) worked and the importance of hydration (gallon water jugs were given to each participant) were the education topic. It was requested that participants drink a minimum of 8 glasses (64 ounces) of water daily. A displacement demonstration shown was to explain building muscles and fat reduction.

Participants' pre-intervention food and activity logs were collected. Fitness goals were discussed as the remaining baseline weights were posted on participants' graphs. Possible concern with weight and body shape, goal setting, and use of graphs to track progress was discussed. Individualized study notebooks were given to each participant, with Healthy Choice materials added as taught. A goal of this project was for participants to have the tools and knowledge to continue healthy exercise and nutrition choices after completion of the study. New concepts were presented after old concepts were reviewed based on paper-pencil assessments.

#### Table 21

#### HEALTHY CHOICES: NUTRITION AND HEALTH TOPICS

Week 1: Introduction; body systems (lean and fat); bones and muscles basics (biceps, triceps); hydration; notebooks and water containers distributed Week 2: Importance of healthy eating, calorie-energy concept Importance of being active to health, and exercise pyramid Introduction of calorie-energy; exercise intensity of duration Introduced daily practice of eating 100 less calories & taking 100 more steps Muscles added: calf, lateral Week 3: Self-determined choice, Weight and inches (muscle and fat); BMI; toning muscles Goal setting, graphs Food groups and caloric content (substitutions and modification) Muscles added: quadriceps and abdominal Week 4: Food pyramid Energy balance equation Review muscles previous introduced Muscles added: Pectorals and hamstrings Week 5: Food pyramid and food groups Importance of balanced eating approach (fad diets discussed) Fast foods (favorite foods and locations) Calories and food labels Concept of making "less bad choices" Week 6: Heart function and heart rate (resting and target heart rates) Aerobic exercise (continuous movement to raise heart rate) Serving size and portion control; food labels The activity pyramid (pre-intervention activity level) Week 7: Importance of staying active Exercise (repetitions, sets, duration, frequency, and intensity) Difference in activities with and without health-benefit Energy balance equation (calories burned) Review energy balance equation, food and activity pyramids Week 8: Importance of regular strenuous (vigorous) exercise to health-related fitness Exercise videos and music tape programs Week 9: Food content labels and fast food nutrition information High frequency foods that appeared on food and activity logs. Meal calorie content (unlabeled) estimated using calculators Substitution of less poor food choices Comparison of labels from foods eaten by the group Week 10: Serving size (portion control) Beverages (content labels, calories, and multiple servings) Comparison of calories by serving size (food and beverage) Healthy portion size with familiar objects for size reference (deck of cards) Portion controlled meals, packaged and unpacked with food models

Week 11: Concept review, demonstrations, and activities

Week 12:	Post-intervention measurements Review and questions – answer Aerobic fitness through music and dance Certificates
Healthy Si	nacks and Hydration:
5	Water (regular and flavor test)
	Vegetable snacks
	Fruit snacks
	Prepackaged snacks (fruit and pudding cups)
	Smoothies (including protein shakes, and fruit shakes)
	Cherry limeade drinks
	France tracts (auch as france fruit frances and drives)
	Frozen treats (such as frozen fruit, freezer pops, and drinks) Frozen yogurt, sherbet, sorbet
	Low-cal shakes
	Popcorn, rice cakes (and variety snacks)
	Participants' favorite snacks

*Note: Exact sequence may have varied due to needs of participants during the program.* 

Although Thursday exercise sessions followed a flexible structure, procedures and rules were defined for participants' safety. The procedure to transition from education to exercise training was provided. Participant notebooks were placed in the foyer, to be retrieved and taken home at the end of the evening's session. Participants were instructed on where exercise mats and hand weights were located and how to safely obtain them. Exercise equipment was placed on the perimeter of the gym floor, and instruction in their safe use was provided after warm-up portion. Instruction on putting away equipment at the end of all exercise sessions was provided. The first week of intervention set the sequence for exercise sessions that were directed by the certified personal fitness trainers, with assistants available to help during whole group or with individual participant needs.

Exercise began with several warm-up laps around the gym, followed by whole gym large muscle exercises (such as reverse run, lunge, sumo squat) and wall exercises (such as the chair, toe and leg raises). Next, mats and weights were placed on the floor for group exercises. Standing next to the mat, participants took part in floor workouts lead by the certified personal fitness trainer (such as jumping jacks and curls with weights). Participants then sat on mats for floor exercises (leg lifts, push-ups, and plank), followed with weight training.

The cool-down portion followed (head circles, flexibility stretching, and breathing) and ended the exercise workout. Participants put away exercise equipment with assistance given by fitness trainer and researcher.

The Sunday exercise session was held at the athletic club by the second certified personal fitness trainer. Participants were met in the lobby by the trainers and preceded to the second floor exercise room (using the stairs). Trainers instructed the participants how to use the recumbent bikes (foot adjustments and gauges); the first ride lasted 15 continuous minutes. Everyone had water and towels. Participants then moved downstairs (via stairs) to a group exercise room. Restrooms and towel bins were pointed out along the way. Location and access to mats and weights was included in the first session. The same sequence for workouts used on Thursday evening (warm-up, exercise, cool-down) was

followed.

Week 2: The first oral paper-pencil assessment was given verbally to assess initial knowledge of concepts and terms related to nutrition and physical activity choices and benefits that would be presented during instruction. Introduction to physical activity choices (exercise pyramid), body benefits (triceps, biceps, and a demonstration on popping arm muscles was presented), and importance of being active to health-related fitness were the instruction topics. A demonstration of how arm movement stretches muscles was included. Instruction included picture cards with an opportunity to select the healthiest activities and foods. The concepts of calorie-energy, duration, and intensity of exercise were introduced, followed by a brief check to determine understanding of material presented. The practice of eating 100 less calories and taking 100 more steps a day was discussed. The planned exercise activity followed and stressed biceps, triceps, and increasing muscle size. The session ended with preparation of vegetable snacks. Sunday exercise at the athletic club followed the planned sequence.

Week 3: Thursday's topic was self-determined goal setting (target line) and tracking self-initiated exercises with graphs and check sheets after a short assessment. The difference between muscle and fat weight (an abstract concept that is difficult for many persons without disabilities to understand) was discussed and reinforced by the trainer. Quadriceps and abdominal muscle groups were discussed.

Nutrition topics for the third session included caloric content, food groups, substitutions, and realistic fitness and weight goals (such as no more than two pounds weight loss per week). A post-intervention assessment over the previous week's topics was conducted. Girths in inches were placed at the bottom of individual graphs. The ability to be more fit by increasing muscle tone without loosing weight was discussed. Fruit snacks were presented. The Sunday exercise workout followed the previous weeks' format with step aerobics added.

Week 4: Body muscle groups previously introduced were reviewed after the pre-intervention test. Pectorals and hamstrings were added to calf, lateral, quad, biceps, and triceps, already discussed. A short postintervention oral assessment was given. Card with exercises previously learned were given to participants for their notebooks. The exercise workout was followed by a short presentation on prepackaged snacks (such as fruit and pudding cups, and freezer pops). Sunday exercise at the athletic club followed the established format..

Week 5: The food pyramid was discussed following a short oral pre-test on placing foods in food groups on the pyramid. The importance of following a balanced approach to eating was discussed and several fad diets were reviewed (Atkins, South Beach, and Weight Watchers). Favorite foods and restaurants that appeared most frequently on preintervention food and activity logs were discussed. Food group instruction was provided using food cards developed from logs, with

approximate caloric content included. Food labels were used in the discussion of healthy food choices (including snacks) and substitutions, noting caloric content. The concept of making "better bad choices" was introduced. A brief oral post-intervention assessment was conducted. The primary certified personal fitness trainer led exercise training. Snacks and smoothies (including protein shakes and fruit shakes) were discussed. The Sunday exercise session was held at the athletic club.

Week 6: Heart function and heart rate was the topic that followed the short oral pre-intervention assessment. Aerobic exercise and its benefits to the heart were discussed, including the distinction between resting heart rate and target heart (raising and lowering heart rate was included). The importance of continuous movement during an exercise session to raise heart rate and benefit of blood and oxygen flow was discussed. Participants practiced taking and counting their heart rates during instruction and exercise portions of the Thursday class. A short oral post-intervention assessment was given. Jump ropes were introduced during the exercise session to heighten awareness of heart rate concepts. A cherry limeade snack was prepared and flavored water was taste tested. Sunday exercise at the athletic club included heart rate monitors on the recumbent bicycles.

Week 7: The activity pyramid was discussed following a brief oral pre-intervention test. The importance of staying active was discussed. A discussion was also held on which activities had health-related benefits

and which did not, based on energy expended (calories burned). The energy balance equation was discussed. To maintain weight, participants were introduced to the concept of increasing activity 100 steps and decreasing energy intake by 100 calories. Pre-intervention food and activity log information on weekly activity choices was included, with personal preferences discussed. A brief oral post-intervention assessment was conducted. The exercise session stressed repetitions, sets, frequency, and intensity. A brief snack session that featured frozen treats (such as frozen fruit and drinks) preceded a fun 15 minutes of basketball hoop shots. Sunday's exercise workout included step aerobics.

Week 8: Following a short pre-intervention assessment, concepts of food and activity pyramids, health value of exercise (calories-energy burned and muscles increased) were reviewed. The rationale for changing exercise repetitions in sets, resistance training, duration, frequency, and intensity was discussed. The importance of regular strenuous exercise to health-related fitness was stressed. Exercise videos and music tapes and their connection to health-related fitness were discussed. A brief oral post-intervention assessment was conducted. The primary certified fitness trainer stressed the number of times an exercise was done (set) and rotation (sequence) of exercises learned. A variety of snacks were presented with participant preferences indicated. Sunday exercise at the athletic club followed the study

routine.

Week 9: After a brief assessment, food content labels on packaged foods and fast food nutrition information were discussed. Utilizing the high frequency foods that appeared on food and activity logs, calorie content of meals (unlabeled) were estimated using hand-held calculators. Substitution of better choices for bad food selections was discussed. Participants compared labels from several packaged foods eaten by the group (such as ice cream, yogurt, bacon, bread, and drinks). A brief oral post-intervention assessment followed. The exercise bout followed a discussion of approximate caloric expenditure, and its relationship to daily meals eaten. The short snack presentation included popcorn, rice cakes, and discussion of participants' favorite snacks. Certified personal fitness trainers led the Sunday exercise session.

Week 10: Portion size control was discussed following the brief pre-intervention assessment. Using a calculator, a comparison of calories contained by serving size was conducted using a food and beverage from participant's food and activity logs. The choice of healthy size food portions was demonstrated, utilizing familiar objects as a size reference (such as a deck of cards). Beverage nutrition labels were used to introduce the concept of serving size; it was stressed that a beverage container might include multiple servings. Portion controlled meals, packaged and unpackaged were discussed with food models. A brief oral post-intervention assessment was conducted. The certified personal

fitness trainer conducted the exercise workout and related calories expended to calories contained in familiar foods. The Sunday exercise session was held at the athletic club, led by certified fitness trainers.

Week 11: A review of previously introduced concepts was presented following a brief pre-intervention assessment. Demonstrations and example activities were presented. A brief oral post-intervention assessment was conducted. The fitness trainer conducted the exercise session. Snacks were followed by basketball hoop shots. The Sunday exercise session was held at the athletic club.

Week 12: the certified personal fitness trainer, took postintervention measurements for each participant with an assistant interrater present, prior to exercise. A brief post-intervention assessment was conducted on basic concept program topics. Weights were posted on graphs and results discussed. Post-intervention activity food and activity logs, pedometers, and stamped envelopes addressed to the researcher were provided to participants. Interest in continuing to exercise one time weekly was discussed. The final Sunday exercise session at the athletic club was held; certificates of completion were presented to participants by the certified personal fitness trainers and researcher.

The general exercise and resistance fitness training regime followed at the gym and health club is outlined in (Table 22).

## Post-Intervention

One week following the Healthy Choice program completion,

Table 22

#### HEALTHY CHOICES: SEQUENCE AND SAMPLE OF GROUP EXERCISE WORKOUT

#### Gymnasium Sessions

First Session:	Safe use of equipment and storage location
Getting Ready:	Get exercise equipment (brought water and towels)
Warm-up:	Stretches
Whole gym:	(Cardiovascular and gross muscle endurance) Laps around the gym (1 to 4) Reverse run, lunge, and sumo squat lunge
Wall exercises:	Chair, toe, and leg raises, wall push-ups
Side: leg Arms and On hands	arious positions): jumping jacks, jumping rope, hoops and dribble lifts (top and bottom) toes: push-ups, plank and knees: leg raise and push, leg and arm raise, opposite limb raise leg lifts, crunch, sit-ups, plank, opposite elbow to knee, riding bike
	ght exercises (strength and conditioning): e exercises such as lateral lifts, curls
Cool-down: Head	circles, flexibility stretching, and breathing
Put away exercise	e equipment
	Health Club Sessions
First session: Tra	ainers instructed the participants how to use recumbent bikes and

where mat and weight were located

Getting ready: Participants (brought water and towels) met trainers in the lobby and walk up the stairs to the second floor exercise room

Warm-Up: Recumbent bike (continuous 15 minutes up to 25 minutes)

Exercise floor: Down stairs immediately following bikes to group exercise room

Endurance and cardio: Step exercises, floor exercises

Strength and conditioning: Followed gymnasium sequence

*Note: Exercise options for health-related physical fitness components were provided in Table 20.* 

participants, parents, and the researcher met to discuss individual progress and the graphing procedure used. Food and activity logs were returned to the researcher and the remainder of interviews scheduled for the following week.

# Self-Perception of Weight Change

Participants were asked a single yes or no question, "Did your body weight or body inches change or stay the same during our exercise and nutrition classes?" Participants were then asked "Why?" with answer choices proved: (a) exercise, (b) change in what eaten, (c) exercise and food eaten, (d) I stayed the same, or (e) other comment.

# Maintenance and Follow-up

Participants were provided an opportunity to continue weekly exercise sessions with the researcher for a period of 5-weeks. Basic health and nutrition concept instruction and reviews were not included. Individual weights were measured prior to beginning their seasonal swim practices (1 hour, 3 times per week), which began 5 weeks after the intervention concluded. Weights were taken again 5 weeks into participants' swim practices.

#### Data Analysis

The three-prong research design combined qualitative, quantitative, and applied behavior traditions. Use of different data collection and analysis methods heightened the possibility that new questions might arise and increase the understanding of physical fitness

and quality of life for persons with cognitive disabilities (Berkson, Tandriacchi, & Sherman, 2001). Parallel mixed analysis, also known as triangulation of data sources, provided a rich understanding of study participants and appears to be the most common mixed-method approach used in educational research within the social and behavioral sciences (Tahakkori and Teddlie, 1998). The 1993 Caracelli and Greene typology development strategy for mixed-method analysis was used in this study (Tahakkori & Teddlie). The strategy suggested that a set of substantive categories evolves and provides a framework to apply while collecting and analyzing contrasting data types. Concurrent mixed collection and analysis of the same data decreases the limitations of using a single type of analysis on each data subset within the study. *Data Analysis Strategy* 

In order to determine the power of test analyses to detect significant differences or associations within the data sets, Montcalm and Royse (2002) recommended that these factors be considered: (a) the degree of variability existing in the variables; (b) effect size, defined as the strength of association or magnitude of difference actually existing among variables; (c) sample size; (d) alpha level; and (e) directionality of test did not apply to this research study because research questions were not stated as null hypotheses. The probability (p < .05) of finding results due to a chance occurrence was set at the 95% confidence level. The results of this research study were calculated using Excel and SPSS

(1999) 10.0 computer software. When available, the report of data results included significance of difference, actual correlation coefficient, and sample size (or degrees of freedom), as well as the level of significance and an indication of precision, such as the confidence interval.

#### Descriptive Data

Subject demographic characteristics (such as age, gender, disability etiology, height, voting status, driver's license status, employment/school status, participation in government social income programs, and health information that might influence fitness level) were collected for participants and their parents. The data is included to describe the individuals included in the study.

## Quantitative Analysis

Descriptive statistics (mean, frequency, and range) formed the causal-comparative element of this methodology. Inferential statistics were obtained from t-test comparisons of repeated measures and groups, and correlation coefficients. The independent variable was the Healthy Choice intervention. Dependent variables included conditions pre- and post-intervention, using measures of body composition, and knowledge of basic nutrition and health concepts. Paired-sample and independent ttests were the statistical techniques used to examine mean differences while considering sampling error (Montcalm & Royse, 2002). An analysis of the intervention's effects on body composition was examined to

determine if correlation existed among the currently accepted field methods selected (Hawkins, 1983).

# Applied Behavior Analysis

This single subject research method focused on visual representation and analysis of actions that change (Richards, Taylor, Ramasamy, & Richards, 1999). The A-B design, across participants and time, with periodic probes was utilized during this study (Richards, Taylor, Ramasamy, & Richards, 1999). Graphing, a component of selfinitiated treatment that provides effective feedback and visual movement toward a goal, occurred for variables weight and total inches (Fisher, Green, Friedling, Levenkron, & Porter, 1976). The reinforcement schedule for this study is the authentic praise and encouragement from peer, family, trainer, researcher, and assistants. The study was based on the premise that self-initiated nutrition and exercise choices, made by the participants in this study, were reflected visually in post-intervention anthropometric measurements when compared to graph baseline (Rachlin & Green, 1972). Generalization opportunities for behaviorsetting-time occurred during the study (Drabman, Hammer, Rosenbaum, 1979). Training in exercise skills that could be appropriately generalized to naturally occurring community settings, were incorporated into the intervention program, providing a greater possibility of their future use (Stainback, Stainback, & Strathe, 1983; Vandercook, 1991). Motivation to exercise can be positively affected by external influences such as

socialization opportunities and music (Hume & Crossman, 1992). *Qualitative Analysis* 

The traditional phenomenological approach allowed the researcher, as primary data collection instrument, to gather information from interviews, direct observation, and archives. The qualitative research method allowed rich description of an in-depth look at adolescents and young adults with cognitive disabilities participating in a situation in its natural setting (Frankel & Wallen, 1996). This approach allowed description of the participants' perspectives of taking part in the Healthy Choice intervention, as well as their parent's perspective of their child's lived experience (Creswell, 1998). Quantitative methodology was considered for this portion of the study, however, data that consisted of amounts and degrees along a continuum of more or less, would not tell the kind of story this researcher sought to relate. Thick, rich qualitative descriptive information, from the perspectives of participants and their parents, was gathered utilizing lengthy semi-structured interviews. Multiple data sources (such as interviews, archived material, questionnaires, and field notes) were used to gather added information.

Qualitative analysis followed Moustakas' four procedural levels of phenomenological theory development (Creswell, 1998). Interviews were categorized into emerging nonrepetitive themes with nonoverlapping statements developed. Results from interviews and member checking were divided into meaningful thematic units with example quotes

identified by pseudonyms. A composite was written that included the essence of interviews, divergent perspectives of interviewees, and investigator's description. A brief aggregate study summary was written that described composite experiences of persons interviewed.

#### CHAPTER 4: RESULTS

The purpose of this mixed-method research study was to describe the effects of a combined program (Healthy Choices) of exercise training and basic health and nutrition education on adolescents and young adults with moderate cognitive disabilities. Parents of participants shared their perceptions regarding the health and fitness of their offspring.

Statement of Research Questions

- Will a program of exercise and basic nutrition and health education have an effect on the body composition of adolescents and young adults with moderate cognitive disabilities?
- 2. Will a program of exercise and basic nutrition and health education have an effect on the body weight of adolescents and young adults with moderate cognitive disabilities?
- 3. Will a correlation exist between field methods selected to estimate body composition in participants?
- 4. Will a program of exercise and basic nutrition and health education have an effect on the knowledge of these concepts in adolescents and young adults with moderate cognitive disabilities?
- 5. From the perspective of participants and their parents, did a program of exercise and basic nutrition and health education have an effect on them?

## Sample Description

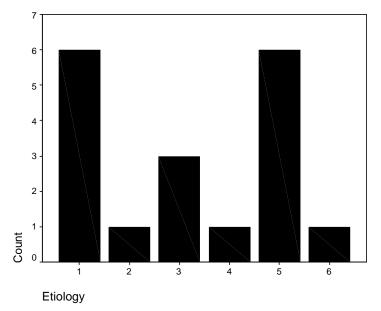
Eighteen individuals with moderate cognitive disabilities from the same organization, with approximately the same opportunities for intervention selection, took part in this study. The primary diagnosis for all sample members was mental retardation (MR) with varied etiology (Figure 6). Activity opportunities for individuals in this organization were approximately the same.

The mean beginning age of the sample was 20.7 years (from 14.5 to 31.5 years; SE 12.05; SD 51.11); mean height was 64.7 inches (5'4.7") (from 59.5" to 72.0"; SE 0.73; SD 3.08); mean base weight was 174.28 pounds (from 105 to 230 pounds; SE 9.21; SD 39.08); and mean BMI was 29.22% (from 19.4 to 39.7; SD 5.98). Descriptive data (including statistical mean scores, range, standard deviations, and correlation coefficients) was used to draw mental pictures of sample members and add dimension to the study. Analysis of this data could provide information about the representativeness of the study sample and generalizability of the research project.

Two groups were formed from the sample, control (n = 7, 3 males and 4 females) and participant (n = 11, 7 males and 4 females). BMI and weights for the individuals in these groups were compared pre- and postintervention. Participants' names were changed for purposes of confidentiality.

#### Figure 6





*Note:* 1 = Down syndrome; 2 = Fragile X – Tourette's syndrome; 3 = Pervasive developmental disorders, including Asperger's and Autism; 4 = Prader-Willi syndrome; 5 = Undetermined origin; and 6 = Cerebral palsy. <math>N = 18.

## Control Group Description

The control group included 7 (3 males and 4 females) adolescents and young adults with moderate cognitive disabilities (Table 23). One member of the control group took part in the pilot intervention one year earlier and had maintained a 20-pound weight loss with the support of her family, by eating nutritiously and continuing an active lifestyle. The mean age of the control group (19 years, range 15 to 23 years) was a little younger than that of the participants (20.9 years). The etiology of the primary diagnosis of MR was: two (28%) with Down syndrome, one (14%) with autism, one (14%) with cerebral palsy, and 3 (43%) from

Healthy	Choice	Healthy Choice Program Control Group (N=7)	-					
					Regular	Govt		Vision
Name	Sex	School/Employment	Age	Etiology	Activity	Fund	Social	Hearing
Connie	Į٦	School	17	Undetermined	ch, s		Ω	
	Ŀ	PUT Commonitient	r C	Down conduction of	َ ک	loo		Ċ
auc	4	ri Compenave	A V	DOWN SYNUTONIE		100		5
Trina	ſŦ,	Sheltered Workshop	23	Undetermined	B, Ba, C	SSI	Ω	
Ben	W	Home schooled	15	Autism	P, B, C			ტ
					• •			
Colin	W	School	19	Undetermined	В	SSI		G, H
Joe	W	Home schooled	19	Cerebral palsy	В	ISS		
Paul	Σ	Home schooled	18	Down syndrome	B. Ba. C			н
		PT Competitive	)					1
Note: A (ac P (physica	laptive F l educati	Note: A (adaptive PE), B (bowling), Ba (basketball), C (Choir), Ch (Church), D (driver's license), G (gla P (physical education group), SSI (supplemental social security), S (Strength & Conditioning), V (vote)	Choir), securit	Ba (basketball), C (Choir), Ch (Church), D (driver's license), G (glasses), H (hearing problems), upplemental social security), S (Strength & Conditioning), V (vote)	cense), G (glas: ning), V (vote)	ses), H (he	aring probl	ems),

Table 23

undetermined origins. Three (43%) of the control group were home schooled, two (28%) attended special education programs (one in the same school district as participants), and three (43%) had graduated.

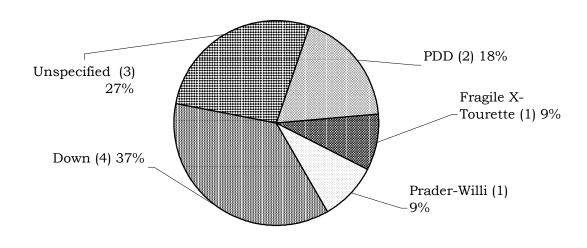
Prior to graduation, two individuals took part in job sampling and vocational technical programs for adolescents through their school district; both now work in competitive part-time food service positions (sandwich shop and school cafeteria). The third graduate worked in a sheltered workshop, after previously working in three part-time competitive positions. One home-schooled individual worked part-time in a business owned by his parents.

Four (57%) of these individuals were receiving supplemental social security income (SSI). All members of the control group were Caucasian. The control group supplied completed physical examinations. Weight and height measurements were performed pre- and post-intervention.

## Intervention Participant Group Description

The intervention group included 11 participants (7 males and 4 females) with moderate cognitive disabilities from varied etiologies (Figure 7). The Healthy Choice intervention combined exercise training and education in basic health and nutrition concepts. One person (9%) in this group was of American Indian descent and the grandparents of one participant (9%) survived holocaust prison camps. There were four (36%) with Down syndrome; two (18%) experienced pervasive development spectrum disorders (PDD) (one with Asperger syndrome); one individual

#### Figure 7



#### ETIOLOGY OF INTERVENTION PARTICIPANT PRIMARY DIAGNOSIS

*Note:* PDD = pervasive disabilities disorder. The number of individuals represented by each etiology is in parenthesis. <math>n = 11

(9%) had Prader-Willi syndrome; one individual (9%) experienced both fragile-X and Tourette syndromes; and three (27%) were diagnosed with moderate mental retardation of unspecified origin.

Table 24 summarizes participants' descriptive data. Participants beginning mean age was 20.9 years, with bimodal frequencies (ages 18 and 22 appeared twice each). Five (46%) of the participants were adolescents (aged 18 years and below) and six (54%) were young adults (between 21 and 31 years of age). Participants all lived with at least their natural mothers, in homes they owned: three had single mothers, mothers of two were divorced, and one mother was a widow. Two had at least one retired parent. Six (54%) males currently attended the same public high school with four (36%) in a job-sampling program; one

					Activity	Govt		Vision
Name	Sex	School/Employment	Age	Etiology	Choice	Fund S	Social	Hearing
Alice	ы	Sheltered Workshop	27	Down syndrome	B, C, W	ISS		Ċ
Karen	ſ <del>z,</del>	Sheltered Workshop	31	Unspecified Mod MR	B, C, W	ISS		Ċ
Krystal	ĹŦ,	PT Competitive	22	Unspecified Mod MR	B, W		D	
Mona	ĹŦ.	Sheltered Workshop	23	Prader-Willi syndrome	B, C	ISS		Ċ
Cliff	Μ	School	14	Asperger syndrome	А, В			
Conrad	W	School, Job Sampling	17	Pervasive Dev Disorder	A, B, Ba			
Dan	Μ	School, Job Sampling	18	Down syndrome	A, B, Ba	SSI, W		Н
Doug	Μ	School, Vo-t <del>c</del> ch	18	Unspecified Mod MR	Ba		>	
John	W	Sheltered Workshop PT Competitive	22	Down syndrome	ß	ISS		Ċ
Jordan	M	School, Job Sampling	17	Fragile X & Tourette	A, B, Ba, C	W		
Matt	W	School, PT Competitive	21	Down syndrome	B, Ba, S	ISS	D, V	G, H

...... Å Healthu Choice Pro

Table 24

worked part-time in competitive supported employment, and one was in a vocational education program. Five (46%) (1 male and 4 females) had graduated from the same school district and all were employed, four (1 male and 3 females) worked full-time in the same sheltered workshop, two (1 male and 1 female) were competitively employed part-time busing tables (school cafeteria and sandwich shop), and one male employee had two jobs (at the sheltered workshop and pizza parlor). Six (55%) received SSI payments and two (18%) were on a waivered services program. Workers at the sheltered workshop were paid piece-mill, and resultant earnings were below minimum wage. The remainder of the employed participants worked part-time jobs for 8 to 10 hours per week at minimum wage. Their annual salaries were less than \$7200.00 and did not reach the \$9300.00 socioeconomic poverty level. Participant pay scales were too low to provide sufficient disposable income on their own, to join expensive fitness clubs or consistently purchase healthy foods.

Preliminary evaluation of pre-intervention data revealed that participants ate restaurant meals an average of 8.5 times per week. Their favorite and most frequently consumed foods were from restaurants and fast food establishments that served beef (burgers, steak), followed by Mexican, and pizza. Parents were pleased their children were taking part in the Healthy Choices study.

# Parents of Sample Members

Lack of complete participant description has been sited as a

weakness of studies, therefore, comprehensive data collected from interviews and artifacts was included. In-depth participant profiles provided an insightful glimpse into the lives that adolescents and young adults with moderate cognitive disabilities lead. The view of family life, social activities, and skills could indicate interventions to enhance their health and lifestyle. Findings supported previous conclusions in the literature that parents can have a tremendous effect on the adaptive behavior and academic success of their children with cognitive disabilities (Zigler, 1987). It is possible for individuals to receive similar IQ scores and function at very different levels (Kozma & Stock).

The study sample might be atypical of adolescents and young adults with moderate cognitive disabilities. The parents were a welleducated group; some attended college, others had received higher education degrees focused on this population, and one was a college regent. Family socioeconomic status was upper middle class or above; some families had two-incomes. These parents continued to work diligently to ensure all their children's future needs will be met. Parents from the group had written transition grants for their school district, created a sheltered workshop, and started or purchased two businesses to employ these individuals with cognitive disabilities. Some parents had begun and monitored group homes, and were working to build an assisted-living high-rise apartment center for their offspring. Parents from this group have been instrumental in starting several recreational

organizations, developing a diversity foundation, and have served on the boards of organizations concerned with the needs of individuals with cognitive disabilities.

Family members of this group were diverse, from those living an alternative lifestyle to survivors of the holocaust. Many parents worked long, stressful hours in white-collar positions with heavy responsibilities and travel; others owned businesses. Two had lost long-term executive positions, and others were retired (voluntary and forced). Recently, parents had gone through a difficult divorce, some were experiencing ill health and chronic disease, and another had committed suicide. The participants of this group were supported and encouraged by their families and others from the group.

#### Individual Participant Profiles

Participants were members of the same seasonal swim team for individuals with cognitive disabilities. According to their abilities, individuals practiced the four competitive swim strokes (freestyle, backstroke, breast, and butterfly) with flip-turns. Six persons attended public schools with community programs: three (Doug, Krystal, and Matt) attended a one-half day program for individuals with disabilities at a local vocational/technical center; five (Cliff, Doug, Dan, Jordan, and Matt) were job sampling. Four participants (Alice, Karen, Mona, and John) worked at the same sheltered workshop five-days a week, 7-hours per day and attended evening bowling sessions every other Friday. Dan

joined them in a church choir comprised of individuals with disabilities that practiced weekly during the school year. Five participants (Conrad, Dan, Doug, Jordan, and Matt) were preparing for Special Olympics basketball competitions and attended twice weekly basketball practices (two-hours per session) that ran concurrently with the study.

*Alice.* Alice was a female 27 years old with trisomy-21, Down syndrome, who wore thick glasses. She was neither as short in stature or as flexible as many individuals with Down syndrome. She had food and inhalant allergies but did not take medications regularly. Alice loved to do crossword puzzles and always had a big crossword puzzle book with her. Alice loved to dance. She usually wore her hair up in a bun. Alice functioned at a high cognitive level, was very confidant, and conversational. Alice was prone to telling tall tales, and as an example, her mother told of Alice's story that "Rod Stewart is my dad" and people had inquired if it was true because she was so convincing. Alice had two older brothers that lived out of state. Alice liked to pretend and when a brother accompanied Alice and her parents to Las Vegas, her brother was upset that she had worn her plastic tiara during an evening out.

Alice competed in several Special Olympic competitions: swimming (50-meter butterfly, 100-meter breast stroke, 4x50 female freestyle relay, and diving), unified bocce and horseshoes, and individual bowling. She was very competitive and only wanted to win first place. She practiced diligently during training seasons, which was evident in the dedication

shown during exercise sessions. Alice's family was very supportive of her endeavors. Her father, brother, and organization founders had been her unified sports partners in bocce and horseshoes. Alice's mom had previously served as her bowling team's coach. Alice did not currently want her mom as a sports partner; she preferred that her mom act as her cheerleader or fan. Alice's mother handled the job well.

Alice craved the attention of individuals other than her parents and was often boy-crazy. Alice walked several times a week with her mom and, over the years, had dieted and worked out with various videotapes. She wanted to lose weight and "have a good bod." Her mom expressed that Alice was eager to attend each exercise workout session and always mentioned the activity before work on scheduled days. Alice usually smiled, was cooperative, and tried hard to get exercise movements correct.

Alice's mother alternated carpool transportation responsibilities (work and all other activities) with another participant's (Karen's) mother, a practice started after joining the organization from which the participants were recruited. Both of Alice's parents worked full-time in middle management positions. Alice had recently become interested in the idea of moving into a planned assisted-living apartment to be close to her circle of friends. Alice required intermittent support.

*Karen.* Karen was a female 31 years old, with a cognitive disability of undetermined etiology, who had echolalic speech. She did not take

medications regularly. She was the tallest female participant. Karen was from a family with four children (2 girls and 2 boys). She saw her four nieces and nephews often and took part in various family activities, including trips to the family farm. Her parents and a sister were very supportive of her activities and endeavors. Karen's father traveled frequently on business and her mother was a busy homemaker that traveled with him frequently. Karen's mother felt that a future group living situation might be fun for her and had mentioned the possibility to her many times. Karen had no interest in living outside their home. Karen's mom felt that the social activities provided by Karen's job were important.

During designated seasons, Karen participated in Special Olympic competitions for swimming (25- and 50-meter breast stroke, 4x50 female freestyle relay, and diving, and had swum in the World Games), team bocce, team horseshoes, and individual bowling. Karen and Matt had been bocce partners for several years and won several tournaments at the state level. Karen and her mother were excited that, for the first time, Karen's sister would be acting as her unified bocce partner during the upcoming season. Karen liked to win, but wasn't visibly upset if she did not place first. She had maintained a consistent practice pace for years.

Karen always smiled and was cooperative. Karen was able to learn and perform a version of most exercises quickly. Although never upset

by a change in exercise sequence, a preference for the same routine was demonstrated as Karen immediately began the exercise she thought would be next. Karen was quiet but could be mildly conversational. She would not ask for help, if needed, which included asking for food or a drink. She enjoyed an annual one-week, out-of-state camp for individuals with disabilities that she attended during the summer. Karen's transportation was usually provided by her mom or the alternating carpooling duties shared with Alice's mom. Karen walked several times a week with her mom. After a few weeks in the exercise program, Karen accompanied her mother to several workout sessions at the YMCA and enjoyed the experience. Karen's parents shared the eagerness she verbalized toward attending each exercise session. Her father stated that participating with her peers was socially motivating but the opportunity to participate in an exercise program with vigorous activity was not always available. Karen required intermittent support.

*Krystal.* Krystal was a female 22 years old with moderate cognitive disabilities of an undetermined origin. She worked in competitive employment during the school year, Monday through Friday for three-hours per day, at an elementary public school cafeteria. Krystal was included in many general curricular classes, beginning in elementary grades and continuing throughout high school. She attended a half-day vocational training program during the last two years of secondary school.

During elementary school, Krystal swam in Special Olympics competitions with her special education class and participated in a therapeutic horseback riding program. She continued to participate in seasonal Special Olympics competitions for swimming (25-meter freestyle and back stroke, and 4x50 female freestyle relay), team bocce, team horseshoes, and individual bowling. Karen had recently discontinued bowling and special church choir activities in which she had participated. She attended a local camp for individuals with disabilities several times a year and participated in their annual ski trip.

Krystal walked with her grandmother two to four days per week. Krystal experienced many problems with coordination and exhibited balance problems when exercising on her side, but worked very hard. Although Krystal's attendance was normally good at planned events, she frequently missed exercise sessions because of transportation problems. Krystal's younger sister often attended intervention sessions with her. Krystal stated that her favorite part of the Healthy Choice sessions was, "the class part...when we talk about food, nutrition and stuff. I can't eat things with skin..." She had been on the Southbeach diet, at her mother's insistence, and lost several pounds. Krystal's family took a 2week family vacation each year and she was eagerly awaiting their first cruise in a few months.

Krystal lived with her younger sister, mother and grandmother, who were all supportive of her endeavors. She visited her dad frequently

but reported that he never attended any activities in which she participated. He was moving out of state soon and Krystal was concerned that she would not see him often. Karen's mom was employed full time and her grandmother was retired. Her grandmother often provided transportation and accompanied her on shopping trips and to various activities. Krystal's sister attended middle school. Krystal's mom had purchased a new home within the previous six months, and Krystal had gotten her first bedroom alone. Krystal had placed her sister's twin bed in her room, so friends could sleepover. Krystal was very social but had difficulty finding friends to do things with. She had a boyfriend for a short while and enjoyed it.

Krystal loved to talk on the phone. Krystal was very conversational and often talked very loudly. Krystal could, but had difficulty with math. Krystal got lost in unfamiliar environments. She was not confident, had braces, loved to buy clothes with her earnings, and frequently worried about her appearance and weight. She earned her driver's license during the study and was practicing the one-mile driving route to her job. Krystal's major transportation was her grandmother and mother throughout the intervention, although Cliff's parents offered an occasional alternate carpool ride to exercise sessions. Krystal required intermittent support.

*Mona.* Mona was a 23-year-old female with Prader-Willi syndrome who had childhood surgery for scoliosis, with spinal rods inserted. Her

mother had done an excellent job monitoring her weight, eating habits, and helping Mona understand the importance of not eating too much. Mona wore glasses and loved to talk to adults. Although always eager to participate, exercises presented more physical challenges for Mona than other participants in the study. She was the shortest in stature, had a thick inflexible trunk, and very small hands and feet (characteristic of Prader-Willi syndrome). Mona's challenges with vestibular balance were apparent when she attempted to get up and down for floor exercises, run during warm-ups, assume various exercise positions, and with initial sessions on recumbent exercise bikes. Mona set bike goals for distance or short time duration during athletic club sessions. She worked hard during all workouts. During designated seasons, she participated in Special Olympics competitions for swimming (25-meter freestyle and backstroke, and 4x25 female freestyle relay) and bowling.

Mona's younger sister attended college a few states away and planned to attend graduate school in the fall in a neighboring state. Mona enjoyed frequent road trips to see her sister and various relatives. Mona's mother was her biggest fan and supported all her endeavors. She was a busy homemaker, with care taking responsibilities for her elderly mother. Mona's sister attended exercise practice when she was in town. Mona's dad traveled on the job and was usually not available for organizational activities. Mona was delighted that he would be taking her, for the first time, to a couple of swim practices and to attend a swim

competition. Mona had a boyfriend in a nearby city and their families dined together once a month. Her mother reported that she liked to play board and card games, with assistance. Mona's mom stated "... she is very competitive and loves beating her cousins and rubbing it in." She enjoyed talking to adults more than she liked being around young adults her own age. Mona was very pleasant, but could be very opinionated and always though she was right. Mona and John's mothers provided alternating carpool transportation. Mona required intermittent support.

Cliff. Cliff was a 14-year-old male with Asperger syndrome who had frequently echolalia. Cliff had difficulty maintaining eye contact, problems focusing on activities, and faced challenges with coordination, and frequent inappropriate social responses. Although home-schooled for a while, Cliff currently attended a self-contained, special education program for students with mental retardation at a local high school. He took part in adapted physical education and job trial at his school. He bowled on Monday afternoons with a group of his peers and on three Thursdays per month with his school. During designated seasons, he participated in Special Olympics competitions for swimming (25-meter freestyle and backstroke, and 4x25 male freestyle relay), individual bocce, horseshoes, and bowling. Cliff liked to participate, but had difficulty focusing his efforts and appeared unconcerned with the outcome. He became disengaged quickly. He was usually pleasant but could become unfocused, agitated, and hard to control, which distracted

other participants during biweekly exercise sessions. He always said hello and hugged people he liked, regardless of the setting.

Cliff was the middle child, with older and younger sisters. His family was very supportive of his activities. His parents had always provided transportation, but his older sister had recently acquired her driver's license and joined the driving pool, relieving their parents of some driving duties. A research assistant provided an occasional ride to weekly sessions. Cliff's dad worked full time in a position that allowed him to work at home frequently. Cliff's mother worked part time and took several annual two-week trips to housesit for her father on the Florida coast. She also had other outside social activities. Cliff required fairly constant support.

*Conrad.* Conrad was a 16-year-old male, diagnosed with pervasive developmental disorder, behavior, and emotional problems. Conrad frequently had a sad face. He had a beautiful smile but did not use it often. He did not interact well with his peers; he was a constant complainer and tattled. He was hyperactive and easily intimidated by others that practiced name-calling or used bad words.

Conrad was the youngest of three brothers who lived with their mother. Conrad's mom was a sales person that traveled the state. Conrad's older brother was attending his first year of college and the middle child was in high school. Conrad's mom was planning ahead for his future and had funded a trust for him with a life insurance policy.

Conrad's mother, nondisabled siblings, and uncle were moving into a new home soon. Conrad's mother planned to use their home in the future as a group home for Conrad and his friends.

Conrad attended a local high school's self-contained program for individuals with cognitive disabilities, which included adaptive physical education. He had not been given the option to participate in the school's job sampling program. Conrad bowled three times monthly at school, and once a week with a group of his peers, and participated in Special Olympics competitions. He practiced basketball and had just begun preparation for flotation swim events. Conrad's attention span was short and he often became disengaged during activities. He was not athletic but was able to learn skills using one-on-one instruction. Conrad's mother was his primary transportation but occasionally carpooled with Dan's mom. Conrad and his mom had begun to spend a lot of time with Dan and his mother. The moms were planning a trip to Las Vegas in the summer without the boys.

Dan. Dan was an 18 year old with trisomy-21, Down syndrome. He was small, wore a hearing aid, had stooped posture, and had an unusual voice quality. Dan had heart surgery when he was young. He attended a local high school's self-contained program for individuals with cognitive disabilities, which included adapted physical education and job trial. He loved to read and particularly enjoyed reading the Sunday paper. He bowled on Monday afternoons with a group of his peers and

on three Thursdays a month with his school. During designated seasons, he participated in Special Olympics competitions for swimming (50-meter freestyle and backstroke, and 4x50 male freestyle relay), basketball, and bowling. Dan was athletic, had historically enjoyed sports participation, and was very competitive. He always wanted to win first place and was upset if he did not.

Dan's parents both worked full time, with long hours. He had an older brother in college that lived on campus. His younger sister attended a different high school in the same school district. His parents and sister had always been very supportive of Dan's endeavors; his brother had never been involved. Dan's parents had recently divorced and he lived with his mother and younger sister. Dan often refused to visit his father's apartment. Dan's behavior problems increased substantially after the divorce and included difficulty in anger control (fights, hitting and choking others), refusal to participate, and acting out to gain attention. Employment obligations were recognized as the reason Dan's parents infrequently provided transportation. Dan's mother arranged for his habilitation-training specialist or Conrad's mother to provide alternate carpooling to Healthy Choice sessions. Dan and his mother had begun to spend a lot of time with Conrad and his mother. Dan required fairly constant support.

*Doug.* Doug was an 18-year-old male with cognitive disabilities resulting from undetermined causes. Many of the characteristics he

displayed were consistent with Aspergers, or those found under the umbrella of pervasive developmental disorders. He was the tallest of the study participants. Doug's adaptive behavior and confidence drastically changed in different settings and with different people. He lived with his mother, step-dad, two brothers and a sister. Both parents worked full time and his step-dad traveled frequently on business. Dan's family was quirky and nontraditional (siblings had spiky, dyed-black hair, chains, and safety pins decorated ears and cheeks).

Doug had attended half-days at a local high school's special education program and participated half-days in vocational training during his last two years of school. Doug's step-dad coached the special basketball team. Doug had bowled in Special Olympics venues in previous years but was not invited to do so during the current school year. Doug's step-dad planned to compete with him in Special Olympics unified golf and 3-on-3 unified basketball venues during the current year. Doug had recently experienced his first Special Olympics golf skills competition with a friend from this group. His attendance at Healthy Choice sessions was spotty, due to transportation problems. His stepdad served as his sole transportation and, along with a younger brother, his only support system. Toward the end of the study he had begun to exercise at the YMCA with his siblings.

*John.* John was a 22-year-old male with trisomy-21, Down syndrome that frequently had ear-tubes. John took medication for a low

thyroid condition and allergies. He had a hearing loss but did not wear hearing aids. He demonstrated hyperflexibility in his joints. He lacked self-confidence, seemed to crave attention, and needed praise. He had good communication skills and loved to talk on the telephone. He loved the new buzz cut he was sporting. John liked girls and often had crushes on female coaches, including a certified fitness trainer. He liked to be directly in front of the trainer during exercise sessions and was one of the hardest workers during exercise sessions. He was always very polite and helped check that all equipment was put away.

John and his older brother lived at home with their newly retired, former schoolteacher parents. His parents attended his athletic practices and competitions, but never his brother. John was working in his second sheltered workshop; he was unhappy at the first one he had worked in immediately after high school. John also worked part-time on weekends, bussing tables at a local pizzeria with his brother. John had begun to spend a little of the money he earned, but his parents saved most of it for the future.

During designated seasons, John participated in Special Olympics competitions for swimming (25-meter freestyle and breaststroke, and 4x25 male freestyle relay, and diving), and bowling. John always wanted to win first place and would pout if he didn't come in first place. Small outbursts were followed by apologies soon afterward. John required intermittent support.

Jordan. Jordan was a 17-year-old male, fraternal twin, with an interesting combination of fragile X and Tourette syndromes, with emotional and behavior problems. His mother was an identical twin. Jordan and his twin sister lived with their parents. He had beautiful blue eyes. Characteristic of fragile X, he had a cherub, pixie-like face, turned-in toes, and arms often bent upward at the elbow with hands flapping. Jordan was hyperactive, talked constantly, had a short attention span, was distracted easily, and often did not interact well with peers. Jordan's behavior issues and apparent sensory integration issues mirrored characteristics of persons with a pervasive developmental spectrum disorder. Although empathetic, he frequently hurt his peer's feelings by calling names or acting out. Jordan often displayed more interest in his peer's actions than his own and had to be redirected and reminded to focus attention on his own activities. He distracted peers and tattled frequently if he did not feel their behavior was appropriate. Jordan demonstrated limited self-awareness, had problems sustaining friendships, and was prone to fighting. The severity of his behavior problems increased if certain foods were eaten, or by time of day. He no longer took Ritalin.

Jordan did his own laundry and picked the clothes he wore to practice independence. He bowled three times a month with his class from school and once weekly with a group of friends. He participated in Special Olympics swimming and bowling venues. He enjoyed wearing his

swim team t-shirts almost daily. Jordan slept nightly on his bedroom floor because he did not want to sleep on a bed. He craved attention. Jordan enjoyed the Healthy Choice program and his increased muscle tone was quite remarkable. His mother stated he had not previously paid attention to nutrition basics she had tried to teach him. Jordan fidgeted and was always looking for something to get into. He was infatuated by the pedometer and wanted to wear it constantly; he broke three and the researcher replaced two. Jordan's primary transportation to exercise was provided by his habilitation-training specialist, with his mother acting as backup. He enjoyed having his mother come to Healthy Choice sessions, however, his behavior deteriorated when she did, forcing her to leave and return at the end of sessions. Jordan's dad worked very hard at helping coach and transport Jordan's basketball teammates to and from practice. Jordan's father attempted to manage Jordan's challenging behavior during practices. Jordan had difficulty focusing his efforts.

Jordan attended a self-contained program at a local high school that included adaptive physical education and job trial. He had low academic skills and was unable to read or do math; hyperactivity was probably a factor. Jordan's twin graduated from high school shortly after the Healthy Choice study ended. Jordan will attend high school for two more years. His parents planned for him to move to a private group facility with friends immediately after high school graduation. To enable

him to be independent from his parents, Jordan spent a lot of time with habilitation specialists and aides, who frequently provided transportation and supervision.

Jordan's parents were authors that ran their foundation from home. They frequently had speaking engagements or were involved in projects away from home. Jordan loved to cook under his mother's supervision. She was a very small neat lady that practiced yoga, was a nutrition specialist, and a vegetarian. She visited a herbalist infrequently, when family members were ill. Jordan required constant support.

*Matt.* Matt was a 21-year-old male with translocated Down syndrome, born with bilateral metatarsus adductus, an atresia, and lacking a tear-duct canal. He began wearing glasses at 18-months of age to correct a traveling eye and farsightedness. When two and one-half years old, he had a tonsillectomy to relieve sleep apnea. He was diagnosed as hugely allergic and took weekly shots and twice daily allergy medications to alleviate symptoms. He also took thyroid medication and sporadically experienced respiratory and gastrointestinal difficulties.

A national journal paid Matt to publish and reprint a paper that he and his mother had written. Matt had earned his regular driver's license, and voted regularly in elections. He enjoyed watching CNN and the History Channel with his dad. Matt was quiet but liked to be with his

friends and family. He was self-conscious about his speech and did not like to repeat himself. He chose not to participate in available group choir and bowling nights. He had difficulties making social contacts and arrangements because he did not like to talk on the phone, due to a hearing range problem. Although he regularly failed hearing screening tests, private hearing assessments had not indicated the need for a hearing aid. Matt used a cell phone to let his family know if his schedule changed or if he needed something.

Matt was enrolled in special education and included in many general curricular classes in middle and high school. He loved sports and had received five letters from his school district. Matt was attending his last year of high school half-days to complete history requirements, take his elective third year of photography, and strength-conditioning physical education classes. He had chosen not to return to the school's half-day vocational training program from the previous year. He worked half-days at a competitive job, sponsored by his school and Vocational Rehabilitation, and hoped to be hired after graduation.

Matt was quite concerned about his weight and physique. His level of physical activity had been reduced due to his schedule. Jazz and tap studio dance lessons (taken for four years with special friends) ended. He no longer had physical education electives or continued high school swim team training. Matt understood that exercise made him stronger, gave him more energy, and there was some connection to weight.

Matt lived with his parents, a recent retiree and graduate student. They supported all his endeavors, as did his aunt, cousins, and grandparents. Two half-sisters and nieces lived out of state. Matt enjoyed traveling; his favorite place was St. Thomas. He wanted to visit England and Switzerland in the future. He had flown alone to visit friends and family in California, Arizona, and Texas. During designated seasons, he participated in Special Olympics competitions for swimming (100 meter freestyle, 50 meter backstroke, breast stroke, and butterfly, with competitive flipturns, 4x50 male freestyle relay, and diving), basketball, golf, power lifting, bocce, horseshoes, and bowling. Matt was athletic, muscular, enjoyed sports, was competitive, and wanted to win. He had learned that some activities were done for fun and it was not always necessary to win first place. He enjoyed coaching younger athletes and those with lower ability levels. He also participated in Very Special Arts, winning best of show in photography and art competitions. He was a huge sports fan and loved following Oklahoma college football and basketball.

## Quantitative Data Analysis

A priori quantitative analysis included two phases: (1) exploration and description of data, and (2) formal statistical analysis. Microsoft Excel and SPSS (version 10.0) software were used to calculate statistics for the quantitative data collected during this study. Descriptive information was included when pertinent. The *t*-statistic was utilized to

compare the means of data obtained when exploring group dependent variables (Montcalm & Royse, 2002). Significance was set at the 95% level of confidence (p < 0.05) recommended in the field of psychology (Kinnear & Gray, 1999). BMI, derived by several field methods, was included as a dependent variable because it is an indication of body composition related to health. Weight was included as a dependent variable because it was used most frequently in the review of literature and appeared to be the measure most understood by participants.

Effects of Healthy Choice Program on Selected Measures Question 1

The first research question was: Will a program of exercise and basic nutrition and health education have an effect on the body composition of adolescents and young adults with moderate cognitive disabilities?

*Comparison between groups.* The control group in the study consisted of individuals with moderate cognitive disabilities that lived in the same regional area, belonged to the same organization, and participated in essentially the same activities during the same time frame as the other study participants taking part in the Healthy Choice intervention. The control group had 7 members (3 males and 4 females), while the intervention group consisted of 11 (7 males and 4 females). Gender and etiology were considered as possible confounding variables to body composition. Independent t-tests were used to compare repeated

(pre- and post-) BMI means (using Quetelet's formula) between the unequally sized control and participant groups (Table 25).

Lavene's test for equality of variances determined that the differences in means between these groups were not significant for: (a) gender [t = -.260; df 16; NS]; (b) etiology [t = -.999; df 16; NS]; and (c) BMI pre- [t = 1.066; df = 16; NS] and post- [t = .630; df = 16; NS] estimates of percent body fat. The homogeneity of variance assumption was not violated and equal variances were assumed between the control and intervention group. There was a 95% level of confidence that the resulting differences between groups, obtained during the intervention, were not a chance occurrence (p < 0.05).

*Participant group.* Paired-samples t-tests were used to compare group means of repeated measures on body composition, while

#### Table 25

			Mean	
	Control	Participant	Difference	<u>Coefficient</u>
Pre-	27.35	30.43	-3.08	0.671
SD	6.9	9 5.28	3 1.71	
SE	2.6	4 1.59	9 1.05	
Post-	27.36	29.18	-1.82	0.678
	7.0	1 5.24	1.77	
	2.6	5 1.58	3 1.07	
Net Diff	-0.01	1.25		

independent-samples t-test (p < 005).

considering sampling error in this within-subjects experiment (Montcalm & Royse, 2002). The repeated measurement technique proved an efficient use of time and resources because group and individual difference data was available pre- and post- intervention. Extensive use of individual participant data was possible, because each acted as their own control. The ability to separate variances cut down data noise. No outliers were noted on a scatterplot prepared before conducting further tests. The paired-samples t-test analysis compared means from the same dependent variables at different points in time (pre- and post-) for the same participants, rather than to a population mean (Montcalm & Royse, 2002). The correlation coefficient (0.998) for the paired BMI variables (mean = 1.25%; SD .33) was significant (p < 0.001). BMI in this repeated measures test was calculated by Quetelet's metric formula  $(W[kg]/H[m]^2)$ . Table 26 summarizes significant differences (t = 12.514; df = 10; p < 0.05) were indicated by the means of repeated measures (pre- [30.43%; SD 5.28; SE 1.59] and post- [29.18%; SD 5.24; SE 1.58]).

Table 26

PARTICIPANT GROUP	P BMI (W/S²)			
	Pre	Post	<u>Difference</u>	Sig (2-tailed)
Mean	30.43	29.18	1.25	.001
Std Dev	5.2760	5.2373		
SE	1.5908	1.5791		

*Note:* N=11; *Std Dev* = standard deviation; S = stature or height; SE = standard error of the mean; W = weight. Quetelet's metric formula was used.

*Control group.* Paired-samples t-tests were performed to compare the means of the control group's repeated BMI measures (Quetelet and CDC online techniques) for the span of time the intervention took place. Analysis (Table 27) revealed no significant difference in BMIs had occurred for this group during the specified timeframe using either the Quetelet (t = -.810; df = 6; NS) or CDC online (t = -.750; df = 6; NS) methods.

*BMI results.* Comparison of the paired t-test findings for the control and participant groups support the finding that an intervention of exercise training and basic health and nutrition education can have positive effects on the BMI of adolescents and young adults with

Та	ble	27
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CONTROL GROUP BI	MI COMPARISONS			
	Pre	Post	<u>Difference</u>	Sig (2-tailed)
Quetelet BMI (W/S²)				
Mean	27.30	27.36	-0.06	0.449
Std Dev	6.89	7.00		
SE	2.60	2.65		
CDC Online Calculat	ion			
Mean	27.26	27.30	-0.04	0.482
Std Dev	6.86	6.99		
SE	2.59	2.64		

Note: N=7; Std Dev = standard deviation; SE = standard error of the mean; Quetelet's <u>metric formula was used</u>.

cognitive disabilities, as demonstrated by the significant improvement in the participants' BMI means, while no significant difference occurred for the control group.

In search of an effective, simple to use, and easy to distribute method for estimating body composition for this population, multiple methods were used to assess the significance of body composition differences, resulting from the intervention studied within the participant group. Significant findings were demonstrated by paired-t-tests using different methods to estimate body composition (Table 28): (a) CDC online BMI calculator [metric or English] measurements [t = 10.237; df = 10; p < 0.05]; (b) sum of three skinfolds [t = 5.005; df = 10; < 0.05]; (c) tabled sum of three skinfolds using standardized tables [ACSM, 1995] [t = 6.521; df = 10; < 0.05]; and (d) standardized BMI table in English measurements [NCHS, 2000] [t = 4.938; df = 10; < 0.05].

Body circumference (girth) measurements are considered an important indication of the distribution of body fat that is linked to health (CDC, 2004; NHLBI, 1998). Waist circumference relates to abdominal adiposity and is considered when screening for the risk of developing cardiovascular disease. Personal trainers considered BMI and girth (sum of total inches) measures to be a true reflection of body composition change, due to exercise and healthy eating. The differences in the group means of waist and sum of 5 girth measurements (upper arm, waist, thigh, and calf for both genders; plus hips for females or

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N-11	Weight	Onetelet's	Total	Sum of 3	CDC Online	ACSM (3	NCHS
T T - M		BMI W/S <sup>2</sup>	Inches	Skinfolds	BMI (lb/f, i)	skinfolds)	(lb/ ft & in)
		(metric)	:				
Bacinning	179.73	30.43	124.91	124.91	30.40	32.94	44.13
Fnding	172.54	29.18		117.18	29.11	31.89	42.59
Mean Diff	7.18	1.25		7.27	1.29	1.04	1.44
Ctd Dav	1 72	33	1.77	5.12	.42	.53	96
SE of mean	5101	9 996E-02			.1261	.1603	.2909
	13 836	12.514			10.237	6.521	4.938
sig (D.tailed)	000	000		.001	000	000	.001
Pair Correlation	666	866.	766.	.992	766.	266.	1.00

Note: 95% confidence interval of the difference. Degrees of freedom for all pairs is 10.

chest for males) for participants were considered in paired-t-test statistical analysis. Participants' pre- waist measurements ranged from 33 to 46 inches, while post- were 31.5 to 44 inches. The sum of preintervention girth measurements ranged from 73.50 to 79.50 inches with post- between 68 and 79. Analysis (Table 29) revealed significant correlation coefficients (p < .001) for the paired dependent variables waist (.934) and total inches (0.997).

#### Table 29

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		Pre	<u>Post</u>	<u>Difference</u>	<u>Coefficient</u>
<u>Waist</u>	Mean	38.77	38.32	.45	.934
	Std Dev	4.21	4.44		
	SE	1.27	1.34		
<u>Total</u>	Body Inches				
	Mean	124.91	121.32	3.59	.997
	Std Dev	21.87	21.07		
	SE	6.59	6.35		

PARTICIPANT GROUP WAIST GIRTH AND TOTAL INCHES

*Note:* N=11; 95% confidence level (p < 0.05); Std Dev = standard deviation; SE = standard <u>error of the mean</u>

*Fat distribution results.* The difference in the mean of participants' BMI indicated that estimates of body fat dropped significantly during the intervention. Participant pre-intervention BMIs are included in Table 30 and were compared to the NHLBI (1998, 2004) National Obesity

Table 30						
PARTICIPANTS'	BASELINE B	MI LEVELS AND RISK	PARTICIPANTS' BASELINE BMI LEVELS AND RISK OF DEVELOPING CHRONIC DISEASE	RONIC DISEA	ISE	
Weight Level	Obesity Class	BMI (kg/m²)	Risk of Obesity- Associated	Particip (Grou Total	Participants' BMI Frequency (Group Mean 30.43%) al Male Fem	tency ) Female
Underweight		Below 18.5%				
Normal		18.5% 24.9%	·	0	1 (24%)	1 (22%)
Overweight		25.0% – 29.9%	High	ო	2 (26, 28%)	1 (27.8%)
Obesity	I	30.0% 34.9%	Very High	ო	2 (30, 32%)	1 (32.7%)
	II	35.0% 39.9%	Very High	ო	2 (37, 39%)	1 (35.7%)
Extreme Obesity III	y III	2 40.0%	Extremely High	11	-	4
Note: Adapted from and CDC (2004).	the table of NII	H obesity education classi	Note: Adapted from the table of NIH obesity education classification of categories of obesity in C. J. Crespo and J. Arbesman (2003, and CDC (2004).	esity in C. J. Cre	spo and J. Arbesm	an (2003,

Education Initiative guidelines to assess obesity class, weight level, and risk for developing chronic obesity-associated diseases (Crespo & Arbesman, 2003). Six participants had BMIs of 30% or greater and were considered obese (4 males and 2 females), three were overweight (2 males and 1 female), and only two (1 male and 1 female) were considered as having normal weight status. When the risk of developing chronic obesity-associated health disorders was assessed, using BMI baselines, 9 of the 11 (6 males and 3 females) were overweight and at high to very high risk, and 6 of the 9 (6 persons, 4 males and 2 females) were considered obese and at very high risk.

Waist girth of 35 inches or greater for females and 40 inches or greater or males indicates a significant risk of developing obesityassociated diseases (CDC, 2004; Crespo & Arbesman, 2003; NHLBI, 1998). Prior to the intervention, 7 of the 11 participants were above the waist girths determined unhealthy, and four individuals (3 males and 1 female) were at or below the suggested girth. After the intervention, 6 participants (4 males and 2 females) were at or below the minimum girth suggested, and 5 were above, with some coming closer to the suggested waist girth limits (1 female was within ½ inch). Activity, nutritional habits, and family history were also factors considered when assessing the risk for developing obesity-associated diseases (CDC; Crespo & Arbesman). Estimates of body fat were also compared to the ACSM (1995) fitness categories and 10 of 11 participants were found to be in

the poor to very poor fitness ranges (1 was in the fair range).

The participant group's pre-intervention mean BMI (30.43) was 3.08% greater than the control group's (27.35). After the intervention, the gap between BMIs had closed to 1.25%. The participant group's BMI had dropped significantly (29.18) while the control group's BMI had increased slightly by 0.01 (27.36). The participant group's mean BMI had placed them pre-intervention at a very high risk of developing an obesity-associated chronic illness. Although still of concern, participant group post-intervention risk had moved from the very high to high-risk category. The results of this intervention support the theory that a program of exercise and basic nutrition and health education could improve the body composition of individuals with moderate cognitive disabilities and improve their health. The possibility of a relationship between the several field methods used to estimate body fat percentages within study participants is discussed in question 3.

### Question 2

The second research question was: Will a program of exercise and basic nutrition and health education have an effect on the body weight of adolescents and young adults with moderate cognitive disabilities?

*Comparison between groups.* The differences between body weight means (pre- and post-intervention) for control and participant groups (Table 31) were compared by independent t-tests; gender and etiology were considered. Results revealed that the mean difference between

#### Table 31

			Mean
	Control	Participant	Difference
Pre-	165.7	179.7	-14
SD	43.08	37.42	1 5.67
SE	16.28	11.28	3 5
Post-	166.1	172.5	-6.4
	43.80	37.18	3 6.62
	16.56	11.22	1 5.35
Net Diff	-0.44	7.16	

groups on base weight (t = .731; df 16; NS) or end weight (t = .333; df 16; NS) was not significant. The homogeneity of variance assumption was not violated and equal variances were assumed between the control and intervention groups.

Participant group. Paired-samples t-tests were used to analyze within group mean differences on weight pre- and post- measurements to determine if effects of the treatment were significant. Few obesity intervention studies in the literature on individuals with cognitive disabilities assessed body composition; weight was the most frequently occurring dependent variable. Weight alone does not account for body type or composition. Increased waist size is a marker for increased obesity linked diseases, even in persons with normal weight (Crespo & Arbesman, 2003). Weight was included in this study for easier

comparison to previous research and because it is often used in day life and field research studies in combination with other anthropometric measures (such as inches and girth) to estimate percentage body fat. Participants in this study ranged in height from 4'10.5" (58.5 inches) to 6' (72 inches) on pre- and post-intervention measurements. Participant base weights ranged between 112 and 225 pounds. Their postintervention weights ranged between 107 and 219 pounds. The correlation coefficient for paired weights (pre- and post-) was 0.999. The group mean weight change (-7.18 pounds; SD 1.72; SE 0.5) in this study, analyzed by paired-t-tests, was significant (t = 13.836; df = 10; p < 001). A summary is provided in Table 32.

#### Table 32

	Pre	Post	Difference	<u>Sig. (2-tailed)</u>
Mean	179.73	172.54	7.18	.001
Std Dev	37.41	37.18		
SE	11.28	11.21		
Note: N=11; 95 error of the me	5% confidence level (p · an	< 0.05); Std Dev = st	tandard deviatio	on; SE = standard

### PARTICIPANT GROUP WEIGHT DIFFERENCES

### Question 3

The third research question was: Will a correlation exist between field methods selected to estimate body composition in participants?

Selection of appropriate methods and reference tools, to

expediently estimate the body composition of individuals with cognitive disabilities included in this study, was tedious. Many individuals with moderate cognitive disabilities experience syndromes and are shorter than the general population average (Chumlea & Guo, 1992; Gunay-Aygun, 1997; Roche, 1965; 1967). Because standardized weight for height ratio tables and nomograms were normed on the population without disabilities, all individuals in this study did not fall within the table dimensions (such as Metropolitan Life Insurance Company, 1959; NCHS, 2000). It was possible to extrapolate approximate BMIs from the tables distributed by United Health Foundation (created by the NCHS, 2000). Neither nomograms nor standardized weight for height ratio tables were located in the literature for individuals with cognitive disabilities or for syndromes specific to participants in this study. The frequently used Metropolitan Life (1959) Desirable Weight Table included bone-frame choices for weights at specific heights, but did not include BMI estimates. The two nomograms considered for the study were problematic, partially due to the narrow fields of anthropometric measures included. A visual review of scatter plots comparing pre-BMIs revealed erratic individual participant points with little correlation appearing to exist between nomograms and other methods selected for the study. Earlier research by Roche stated that printing errors could occur with nomograms, causing the body fat percentage line to be askew, producing inaccurate BMI estimates.

Several techniques (see Table 28) were used to determine the effects of the intervention on participants' body composition: (a) estimate of body fat percentage by BMI [Quetelet's metric W/S<sup>2</sup> formula and CDC created website calculations in feet and inches or metrics]; (b) estimate of body fat using skinfold measurements by gender and age [ACSM, 1995]; and (c) standardized BMI table [NCHS, 2000] determined by weight (pounds) and height (feet and inches). Although body weight, total inches (sum of 5 girths), and skinfolds (sum of 3) were individually considered in question 2, the possibility of their correlation with other estimates of body composition was also considered. The correlation of one nomogram was also considered. Identification of field methods that could efficiently produce similar estimates of body composition for individuals with cognitive disabilities might encourage the pursuit of more intervention investigations, rather than prevalence studies. Scatterplots were utilized to visually examine if linear relationships existed between variables (Kinnear & Gray, 1999). The Pearson correlation coefficient was used to determine the strength of relationship (0.80 = strong, 0.50 = medium, and 0.20 = weak) between methods used to determine body composition (Table 33).

*Correlations with skinfold measurements.* The ACSM (mean = 32.94; SD 6.18) estimates of percentage body fat, based on age and gender related tables of the sum of 3-skinfold thicknesses, correlated only with the other sum of 3-skinfolds estimate (mean = 124.9; SD =

#### Table 33

	$W/S^2$	CDC	ACSM	SF	Inches	Weight	Nomog
Quetelet	-	0.999**	-	0.811**	0.651*	0.854	0.738*
CDC-BMI	0.999**	-	-	0.823**	-	0.655*	0.740*
ACSM-SF	-	-	-	0.625*	-	-	-
Skinfolds	0.811**	0.823**	0.625*	-	-	0.833**	-
Inches	0.651*	0.655*	-	-	-	-	-
Weight	0.854**	0.858**	-	0.833**	-	-	-
Nomogram	0.738*	0.740*	_	-	-	-	_
Note: Signij	ficance (2-	tailed): * =	0.05; ** =	0.01			

CORRELATION MATRIX: ESTIMATES OF BODY COMPOSITION

33.68), (r = .625; n = 11; p < 0.05; ES = 0.39). The relationship was moderate to strong.

The sum of 3-skinfold thicknesses was significantly correlated with: (a) Quetelet's BMI [r = .811; n=11; p < 0.01; ES = 0.66]; (b) CDC online BMI calculator [r = .823; n=11; p < 0.01; ES = 0.68]; (c) ACSM BMI tables by age and gender [r = .625; n = 11; p < 0.05; ES = 0.39]; and (d) total inches [r= .651; n=11; p < 0.05; ES = 0.42]. There was a strong relationship between the sum of 3-skinfold thicknesses with Quetelet and CDC BMI's and moderate to strong relationship with ACSM tables and total inches.

Correlations with BMI. Quetelet's formula (W[kg]/H [m]<sup>2</sup>) to

estimate BMI (mean = 30.43; SD 5.28) was most frequently referenced in literature, and was the basis for many standardized tables. The Quetelet  $W/S^2$  formula was significantly correlated with: (a) the University of Texas nomogram [r = .74; n = 10; p < 0.05; ES = 0.55]; (b) CDC online BMI calculator [r = .99; n = 11; p < 0.01; ES = 0.98]; (c) sum of 3skinfolds [r = .811; n = 11; p < 0.01; ES = 0.66]; (d) total inches [r = .655; n = 11; p < 0.05; ES = 0.43]; and (e) body weight [r = .854; n = 11; p <0.01; ES = 0.73]. The Quetelet BMI was strongly related to the CDC BMI, sum of 3-skinfolds, and body weight and moderately to strongly related to the nomogram and total inches.

The online CDC BMI calculations (mean = 30.40; SD 5.34), both English and metric (r = .99; n = 11; p < 0.01; ES = 0.98) were correlated with: (a) Quetelet's BMI [r = .99; n = 11; p < 0.01; ES = 0.98]; (b) the sum of 3-skinfolds [r = .823; n=11; p < 0.01; ES = 0.68]; (c) total inches [r = .655; n = 11; p < 0.05; ES = 0.43]; and (d) body weight (r = .858; n = 11; p < 0.01; ES = 0.74). The CDC BMI was strongly related between metric and American measures, Quetelet, sum of 3-skinfolds, and body weight. It was moderately to strongly related to total inches.

The University of Texas (Chessher, 1999) created nomogram (mean = 27.1; SD 7.75) was moderately to strongly correlated with BMIs derived from Quetelet's formula (r = .74; n = 10; p < 0.05; ES = 0.55) and the CDC online calculator (r = .74; n = 10; p < 0.05; ES = 0.55). It should be noted that when participant BMIs derived by the nomogram were

considered individually, rather than as a group mean, they varied widely as demonstrated by the scatterplot.

*Correlations with anthropometric measures.* The sum of five girths total inches (mean = 124.91; SD 21.87) is correlated moderately to strongly with: (a) Quetelet's BMI [r = .651; n = 11; < 0.05; ES = 0.43]; and (b) CDC's online BMI calculator [r = .655; n = 11; < 0.05; ES = 0.43]. Body weight (mean = 179.73; SD 37.41) was strongly correlated with: (a) Quetelet's BMI [r = .854; n = 11; < 0.01; ES = 0.73]; (b) CDC's online BMI calculator [r = .655; n = 11; < 0.01; ES = 0.73]; (b) CDC's online BMI calculator [r = .858; n = 11; < 0.01; ES = 0.74]; and (c) sum of 3-skinfolds [r = .833; n = 11; < 0.01; ES = 0.69).

# Question 4

The fourth question was: Will a program of exercise and basic nutrition and health education has an effect on the knowledge of these concepts in adolescents and young adults with moderate cognitive disabilities?

Participants taking part in the Healthy Choices intervention of education in the basics of nutrition and health were assessed with a paper-pencil test prior to introducing any information. The researcher, proxies, and assistants read questions to each individual and marked their answers, if needed. A paired-samples t-test for repeated measures, compared within-group means to determine the effect of the basic education portion of the intervention (Table 34). On the pre-intervention paper-pencil tests, the group mean for correctly answered questions was

#### Table 34

	Mean	Std. Dev	<u>SE</u>	Sig (2-tailed)
Pre-	2.09	1.2210	.3682	
Post-	14.36	3.2641	.9842	
Paired-Differences	12.27	3.2586	.9825	0.01

BASIC KNOWLEDGE OF HEALTH AND NUTRITION CONCEPTS

*Note: Data was obtained as correct answers on repeated measures of paper-pencil tests.* 

2.09 (SD 1.22; SE .3682). On the post-intervention paper-pencil tests, the group mean for correctly answered questions was 14.36 (SD 3.26; SE .9842). Results of the paired-differences t-test analysis of the mean differences of repeated measures on basic concept knowledge were significant (t = -12.491; df =10; p < 0.01).

### **Qualitative Analysis**

The qualitative approach to data collection was necessary in order to address the last question of this study. The analysis of this research methodology was done textually. Data was gathered from narratives, questionnaires, interviews, anecdotal records, artifacts, member checking, observations, and field logs of self-awareness activities (Creswell, 2003). The nominal (categorical) scale of measurement system was used for counting data information without calculations. Data from the multiple sources were coded and analyzed. Only replies pertinent to this study were reported.

#### Participant and Parental Perceptions

## Question 5

The fifth research question was: From the perspective of participants and their parents, did a program of exercise and basic nutrition and health education have an effect on them?

Self-awareness activities. Participant activities engaged in throughout this study were designed to provide personal connections to data obtained and elicit a broad range of in-depth awareness and reflections that might not otherwise be generated by numbers alone. The awareness activities were employed pre-intervention (such as food and exercise logs, pedometer use, and questionnaires). During the treatment knowledge questions, weight graphs, instructional and exercise activities were utilized to increase participants' understandings of health, nutrition, and exercise.

Unsolicited comments made by eight parents, indicated their offspring had increased their awareness in relation to aspects of the study. Anecdotal comments of parents included the following statements: Alice's mother stated, "I had no idea how much we ate out... and how poorly we picked our foods!" Dan's mother stated, "I had not noticed how much we did that really just involved sitting... not, much strenuous activity." Krystal's mother stated, "I'm so tired after work that I just don't prepare nutritious meals... it's a lot of work." Jordan's mother stated, "I want some more copies of that sheet we wrote foods we

ate on. I want to keep track for a while." John's mother stated, "It really makes us aware of what was eaten." Jordan and John's mothers recorded food log information for the entire duration of the intervention. Three other mothers provided occasional food logs during the study. Conrad's mother stated, "... those lists of food eaten... they really made us focus on what was being eaten and we are trying to change it up." Mona's mother stated, "... we are so busy that we eat out a lot... I just didn't realize how much junk we eat."

Anecdotal comments made by participants about awareness activities, included these comments: Mona stated, "See how much I walked today?" Jordan stated, "I walked 1,000 steps after school." Matt stated, "I sure eat a lot of McDonald's hamburgers, don't I?" Nine of the participants talked about wearing the pedometers.

Data resulting from self-reported activities (such as steps moved recorded with a pedometer and target heart rate activity), and answers recorded with proxy assistance (food and activity logs and food preference pre- questionnaires), may not be considered reliable. The process was nonetheless important, because it provided thoughtful glimpses seen through the eyes of these adolescents and young adults with moderate cognitive disabilities and their parents. Generalization of data to the larger population of persons with cognitive disabilities should be cautiously considered.

Interviews. Participants and their parents took part in interviews.

Two parent focus groups were conducted in addition to face-to-face individual interviews that allowed input from each family. Broad topics emerged when interviews were transcribed and coded.

Pertinent topics that emerged from parent focus groups and interviews included:

- Changes attributed to the study (such as awareness of food labels and calories, drinking more water, interested in being active, thinking about calories when eating out, eating in moderation, and program continuation).
- Past physical education or exercise experiences (such as failure to be included, lack of specific sport and exercise knowledge, and attitudes of teachers and peers).
- 3. Motivation for attendance and participation in this study (such as social, to help researcher, graphs, opportunity to lose weight, effect of exercise on muscle tone noticed).
- 4. Barriers to activity and intervention attendance (such as transportation, family issues, lack of opportunities, and experiences).
- 5. Health topics [personal health status, body toning, exercise habits and patterns, weight, exercise equipment, exercise regime sequence, and graphs).

Parental perceptions of change. Parents noticed their offspring's increased awareness of activity and food habits. Karen's mother stated, "Karen and Alice had no idea how many calories any thing had and now

we're looking at labels." Cliff's mother stated, "Cliff thought Hi-C was a good drink... until we noticed there were two servings in the bottle instead of one... and there were more calories than in a bottle of pop." Jordan's mother said she had tried unsuccessfully to change his eating habits; the intervention had peaked his interest and his activity patterns were changing.

Karen and Matt's fathers and Alice and Dan's mothers mentioned consumption of too many soft drinks. Alice's mother asked, "... could you try to make her understand that she can't have an unlimited number of soft drinks and still lose weight?" Conrad's mom stated, "We're trying something new, he drinks water after he has a Coke.... it is reducing his beverage intake."

Seven parents stated that their offspring had not been drinking water regularly. Krystal's mother stated, "Krystal takes her bottle of water everywhere we go now." John's mother said, "John drinks one bottle of water for every bottle of pop he drinks. It is an improvement, he didn't use to drink any water at all." Matt's father stated, "Matt fills a water bottle and freezes it to drink at work." Alice's dad stated, "We keep bottles of water in the frig and she knows to drink at least 8 a day." Mona's mother stated, "I never thought I'd see her drinking water by choice."

All 11 participants acquired exercise mats and free weights for their use at home. Karen's mother said, "Oh yes, we all have the proper

equipment now.... and sometimes we use it.... in fact, we have been a lot."

Parents noticed their offspring's changing physique. Jordan's mother stated, "I'm going to have to get Jordan new pants.... his are falling off, this is great!" Dan's mother chimed in, "I've already had to get new pants for Dan. He couldn't wear the others to school!" Alice's mother stated: "She is wearing clothes that have not fit right for a long time."

Parents indicated a need to continue the exercise and education components of the intervention. Doug's dad stated, "We need to keep doing this together." Conrad's mother stated, "He won't do this alone, we need to continue." Alice's mother hired a peer to workout with her once a week. Karen's mother took her along to exercise sessions at the Y. Conrad's dad stated that they were going to the YMCA more often.

Parents discussed their children's eating habits and discovered that many shared the same patterns. Dan's mother stated, "He eats one thing at a time, like a burger pattie, then moves on to the next thing." Mothers of Alice, Jordan, John, Matt, and Karen expressed their children's eating patterns were the same. John's mother said, "Oh, he always eats the same things.... we just move them around some." Matt, Mona, Conrad, Doug, and Krystal's mothers, expressed similar patterns existed. Barriers to proper eating habits were expressed by Conrad's mother, "I do a very poor job of shopping for healthy things to have

around the house and I don't provide very good meals." Doug's mother stated, "I cook quick things that use the George Forman grill and fryer ...I have got to change the things I cook and the way I cook. Some of the eating habits are my fault." A new awareness of what the participants were eating was named many times by parents. A recurring topic was the quantity of food eaten and how much was consumed from fast food outlets.

*Participants' perception of change*. Ten participants were fascinated with their upper arm and calf muscles. Only two participants had previously popped their muscles, so it became very motivating for them to demonstrate how their arms had changed. Frequently you heard Jordan say, "... look at my muscles, they're very big." Conrad voiced his desires to tone his body by stating, "... I get a 6-pack..."

Awareness of activity and food habits was noticed. Krystal asked, "... did you see what food I ate? I did good, didn't I?" Matt frequently asked, "... did I make a healthy choice?" Jordan stated, "I eat healthy. I have good meals."

### Follow-up

Maintenance was conducted on a voluntary basis for 6-weeks postintervention at the church gymnasium. Participants declined to sign-up for the health club's discounted membership rate (some did not want to workout without the trainer, others had memberships with their parents at other facilities, and some were just tired of the weekly routine). Twice

weekly basketball practices, attended by five participants, ended the same week as exercise sessions. The researcher and an average of four to six participants met at their regular Thursday evening time to dance. The weekly dance activity was not aerobic; it included line-dances, and upbeat music with a few slow dances thrown in to prepare for upcoming celebrations. Participants brought water bottles. We discussed nutrition and health only if the participants initiated the conversation. At the end of 6 weeks' voluntary maintenance, all participants were weighed with a group average regain of 1.9 pounds revealed.

An additional 6-week follow-up was conducted with weekly dance sessions continued once weekly for 4 weeks. Their organization's annual swim practices began the 5th week of the follow-up timeframe and gym sessions ended. All participants attended swim practices during the final two weeks of the follow-up timeframe. Swim practices were voluntary and available one to three times per week for 1 hour each. Swim practices were vigorous training sessions that consisted of warm-up stretching and swimming laps using different strokes, with occasional use of kickboards or pull-buoys. Weigh-ins at the end of this 6-week follow-up revealed that mean weights (171.9) had dropped 2.54 pounds.

The participant group's net mean weight change during the intervention and follow-up was a loss of 7.82 pounds (Table 35). Average estimated body fat percentage was 29.8% (Quetelet's BMI). The participant group's mean BMI change dropped the weight status

classification (NHLBI, 1998; CDC, 2004) from class I obese to overweight with the risk for developing obesity-associated chronic diseases dropping from very high to high.

### Table 35

MEAN WITHIN GROUP PARTICIPANT WEIGHT CHANGES						
	<u>Mean</u>	Std Dev	<u>SE</u>	Wt Change		
Pre-	179.73	37.41	11.28			
Post-	172.54	37.18	11.21	- 7.19		
Maintenance	174.45	35.83	13.54	+ 1.91		
Follow-up	171.91	33.95	12.83	- 2.54		
Net change (pre- thre	ough follow-up)			- 7.82		
Note: Weight is expressed in nounds. Follow-up will continue longitudingly. Std Dev =						

*Note: Weight is expressed in pounds. Follow-up will continue longitudinally. Std Dev =* <u>standard deviation; Wt = weight</u>

#### CHAPTER 5: DISCUSSION

#### Overview

The majority of research on health-related fitness for adolescents with cognitive disabilities has found this population to be less physically fit on virtually all measures, and have more health problems than the population at large (Campbell, 1973; Chanias et al., 1998; Horowitz et al., 2000; Pitetti, Rimmer, & Fernhall, 1993; Winnick & Short, 1999). The prevalence of overweight and obesity was also greater among persons with cognitive disabilities (Harris, Fada, Rosenberg, Jangda, O'Brien, & Gallagher, 2003; Rimmer, Braddock, & Fujiura, 1993). Research informs that individuals with moderate cognitive disabilities living in community settings are less active than persons with mild disabilities, and more likely to be obese than individuals with more severe disabilities (Fernhall et al, 1989; Fernhall & Tymeson, 1987; Fernhall, Tymeson, & Webster, 1988; Fox & Rotatori, 1982; Frey & Rimmer, 1995; Kelly, Rimmer, & Ness, 1986; Kreze et al., 1974; Rimmer, Braddock, & Fujiura, 1993; Rimmer, Braddock, & Marks, 1995; Rubin et al., 1998; Simila & Niskanen, 1991; Wallen & Roszkowski, 1980).

Individuals with cognitive disabilities are largely sedentary (Coleman, Ayoub, Frederick, 1976a, 1976b; Gabler-Halle, Halle, Chung, 1993; Heward & Orlansky, 1992; Maksud & Hamilton, 1974; Millar, Fernhall, & Burkett, 1993). Inactivity has been named as the most common cause of obesity, and sedentary lifestyle was cited as the leading

cause of obesity and low cardiovascular fitness in persons with cognitive disabilities (Campbell, 1973; CDC, 2004; Coleman & Witman, 1984; Dresen et al., 1985; Fernhall, Tymeson, & Webster, 1988; Fox & Rotatori, 1982; Gibson, 1997; Litchford, 1987; NHLBI, 2004; USDHHS, 1996).

Poor motor skills and low fitness levels, rather than motivation, could explain the sedentary activity level in this population (Fiorini, Stanton, & Reid, 1996; Kozub, 2001, 2003). Opportunities to engage in sports programs are lower for individuals with disabilities, who are known to be less persistent and may not be adept at locating activity options independently (Kozub, 2002; Kozub & Poretta, 1998; McDonnell et al., 1993). Attitudinal studies, focused on the general population toward individuals with cognitive disabilities, revealed lack of acknowledgement for the range of capabilities existing in this population (Siperstein et al., 2003). The lowered expectations of this population displayed by the public, may result in fewer community inclusion opportunities, and affect their overall health-related fitness.

Many studies have been concerned with the effect of exercise on body composition in the general population. Even though obesity is a serious problem for persons diagnosed with significant cognitive disabilities, only 10 studies were reported that included any form of exercise (Braunschweig, et al., 2004; Burkett, Lee, & Phillips, 1994; Francis & Rarick, 1959; Howe, 1959; Kelly & Rimmer, 1987; Kelly, Rimmer, & Ness, 1982; Millar, Fernhall, & Burke, 1993; Rarick, Widdop,

& Broadhead, 1970; Rarick & Dobbins, 1972). Body composition was used as a dependent variable in few health-related fitness studies (15 prevalence, 5 measure comparisons and classification) (Chanias, Reid, & Hooper, 1998). None of the associated obesity studies for this population attempted to measure change in percentage of body fat. A healthscreening program to determine prevalence of overweight and level of fitness has been implemented by Special Olympics International. Screening alone has proven insufficient to promote action to lose weight and reduce BMI in this population (Marshall, McConkey, & Moore, 2003; Horowitz et al, 2000).

The current study explored the effects of a combined intervention of basic nutrition and health education with exercise training, called Healthy Choices, on body composition of adolescents and young adults with moderate disabilities, living with their parents. Perceptions of parents and participants lent a deeper understanding of the process. A 95% confidence level was set for statistical analysis of data with many findings significant at p < 0.01.

## **Discussion of Findings**

#### Basic Knowledge Results and Conclusions

The change in participants' base knowledge of health-related fitness concepts changed significantly for the sample of individuals with moderate cognitive disabilities (t = -12.491; df = 10; p < 0.01). The group mean score increased 12.27 points after applying the intervention of

basic health and nutrition concept instruction (pre-mean = 2.09 [SD 1.22; SE 0.37; range = 1 to 5] and post- mean = 14.36 [SD 3.26; SE 0.98; range 9 to 19]). Application of this knowledge required the cooperation of parents or other caregivers when grocery shopping, during food preparation, and eating meals (at home or away). The researcher created the Healthy Choice intervention for this study, because a commercial curriculum was not available. During and after the application of the intervention, participants were interested and curious about the information; they were eager to learn. They were attentive and took part in discussions.

# Body Measurement Results

Changes in mean intervention group body size measures were all significant. BMI body fat percentage estimates declined significantly (t = 12.514; df =10; p < 0.05). A significant decline was also seen for total body inches (sum of five girths [t = 6.72; df =10; p < 0.05]) and skinfold thicknesses (sum of three [t = 5.00; df = 10; p < 0.01]). Group mean weight revealed a significant decline as well (t = 13.836; df = 10; p < 001). Two of the four variables were significant at  $p \le 0.01$ . Findings indicate 95% to 99% confidence that results, obtained with the intervention, were not a chance occurrence. This is supported by similar studies on the general population and is consistent with government recommendations for improving health-related fitness (ACSM, 1998; CDC, 2004).

The mean BMI of males in the intervention group was higher than

for females, supportive of early research (Kreze et al., 1974; Nordgren, 1970; Polednak & Auliffe, 1976). The finding conflicted with more recent research (such as Bell & Bhate, 1992; Fox & Rotatori, 1982; Frey & Rimmer, 1995; Kelly, Rimmer, & Ness, 1986; Rimmer, Braddock, & Fujiura, 1992, 1993; Simila & Niskanen, 1991; Wallen & Roszkowski, 1980). The result was partially explained by the greater mean BMI demonstrated by males with Down syndrome (36.5; range 37.9 to 26) in the intervention group, when compared to pooled BMI mean of participants with other etiologies (28.4; range 35.8 to 22.4). Of note, previous Down syndrome studies found individuals with severe congenital heart problems to be smaller than persons without the health problem. Supportive of these findings, one male participant with Down syndrome, who underwent heart surgery during childhood, was found to be both shorter in stature and weight less than his study peers with Down syndrome, but without known heart problems.

The number of participants considered obese, by post-intervention health screening guidelines, decreased, moving into the overweight category. Post-intervention, the number of individuals considered at high risk for developing obesity-associated diseases dropped from 9 to 5. Use of weight as the sole dependent variable in studies is problematic; it is not considered a true indicator of health–related fitness. When used in isolation, weight may not accurately indicate body composition. Muscle can be increased and effect the body fat percentage and distribution, yet,

weight could increase because muscle is more dense than fat. This concept was difficult for participants and their parents to understand. The predisposition to use weight as an indication of fitness was strong within this sample, explaining its inclusion in the study. The use of scales and weight graphs in the study might provide beneficial when tracking long-term skill acquisition. Body size and health-related fitness were stressed over weight, in the Healthy Choices intervention.

#### Conclusions After Intervention

Study results are supportive of the hypothesis that a program of exercise and basic nutrition and health education can significantly lower body composition and risk for developing obesity-associated chronic diseases in adolescents and young adults with moderate cognitive disabilities. An opportunity to take part in the Healthy Choice program will be offered to the control group, and results compared to those of the intervention participants in this study.

# Discussion of Measurement Correlational Results

When the Pearson correlation coefficient was used to determine the strength of relationship between methods used to determine body composition, no significant differences were found between them. The most commonly used method in research to estimate percentage body fat was Quetelet's BMI formula. Converting measurements to metrics was time consuming and cumbersome. The quickest, easiest, and bestcorrelated method to Quetelet's formula, used in the current study, was

the CDC online calculator (r = 0.99; p < 0.01). The process was simple and fast (type height and weight in appropriate blocks and push the calculate button). The BMI reference table accompanied the calculator on the computer screen. Information could be downloaded for metric or American (height in inches or in feet and inches) measurements. The online calculator could be easily used with this population in schools or homes. The CDC offered a new, downloadable, standardized weight – height table to contain percentage body fat calculations up to 54% (morbid obesity), and included a broader matrix range of measurements. Estimated body fat percentages obtained with the online calculator were very similar to those found with Quetelet's formula.

Appropriate, quick formats to estimate percentage body fat from anthropometric measures could enable adolescents and young adults to pursue a program of fitness, set goals and self-monitor their progress. Identification and suggested use of methods that could efficiently produce similar estimates of body fat percentage for this population, might encourage the pursuit of more intervention studies, rather than continuation of prevalence and method comparison research.

# Conclusions from Correlation Study

The CDC online calculator is recommended for individual use or for small studies. Quetelet's formula is appropriate for large groups, with conversion formulas in spreadsheet format for automatic calculation and storage of body fat percentage estimates.

### Discussion of Participants' Perceptions

Participants appeared to enjoy the exercise, instruction, and social exchange during biweekly sessions. They were initially ready to exercise and expend excess calories to lower their weight. An increased determination to build muscles and strength resulted from the intervention and the motivation to build stamina and endurance for their upcoming swim season. Participants demonstrated interest in concepts and application of knowledge acquired, particularly concerned with food (calories and food labels). The benefit of appropriate food and portion size choices was acknowledged when they would ask, "... is this a healthy choice?" Individuals drank more water as a result of the intervention.

Interest in the intervention and its importance, was demonstrated by participants and their parents by their attendance and participation in 12 weeks of twice weekly sessions and completion of outside third hours of exercise. Lack of opportunity to take part in health programs (for this population and in the general population), rather than lack of motivation to participate, was voiced. Although transportation could have been a problem (it was for 3 participants who had multiple absences), the parents creatively carpooled, similarly found for younger children without disabilities in the general population. Although several individuals in the sample had driver's licenses, they made wise decisions not to drive, stating it made them tired, they got lost, or they didn't want to drive in the dark.

### Conclusions from Participants' Perspective

A consensus was reached that programs of this type need to be available to this population on a wide basis. Although improved healthrelated fitness was the overarching goal for the study, social networking was seen as very important. Participants demonstrated application of important concepts and made changes in their routines; need to exercise, eat better, and drink more water were acknowledged as strategies to expend excess calories leading to accumulation of fat. They worked toward common exercise goals of improving their body shape, lowering their weight, and having a good swim season with improved endurance and strength. Work remained to be done in the area of realistic goal setting related to participant and parents' interest in weight loss.

# Researcher's Discussion and Perspectives

The researcher's mention of more energy or stamina resulting from exercise did not seem to spark participant interest. However, when possibilities of these results were placed in the context of their swim performance, it appeared to highly motivate them; all 11 persons were very excited about exercising vigorously throughout the study.

The researcher was surprised that 2 parents kept logs for the 12week intervention; an additional 4 requested logs for future use. Both parents and participants became aware of their eating habits and recognized a need to change. Nine participants voiced a connection between current activity and increased activity levels recorded by

pedometers. Others just liked the gadgetry. Unsupervised, reliable, and correct use of a pedometer for a week was difficult. Participants enjoyed using the graphs because it made the concept of weight less abstract. Although 5 weight probes were charted for each participant, repetition of the task was not frequent enough to build fluency or automaticity. Locating information on each axis was done easily with assistance; the difficulty came in intersecting the information for point placement. Using rulers to connect the dots produced a line that was easily followed, based on weight in relationship to previous postings. The aim line was somewhat confusing and needed to be in a separate color than the probes, baseline points, and progress line.

The older participants seemed to be more focused and motivated to consistently perform exercises to the best of their abilities, with selfmotivation to exercise apparent. The participants did not use audible self-talk during exercise sessions; perhaps self-reinforced task completion was internalized, as it should be. This could be due to the underlying organization of the class exercise experience. Exercise sessions were very structured in nature, and might have provided the necessary sequence of steps and reinforcement needed for task completion.

Difficulties in balance were demonstrated, especially when participants were on their sides, partially toward their backs. The individual with Prader-Willi had the most difficulty with exercises; low

endurance and lack of strength was encountered, which required the use of lighter weights of a different style. Problems staying on task and coordination issues were apparent for the individuals with fragile X/Tourette and Asperger's syndrome. Coordination and activities with multiple foot-steps (such as jumping rope) presented difficulties. Parents revealed that 9 of the 11 study participants could not ride a bicycle, roller skate, or use skateboards, due to balance issues; some of which were thought to be caused by ear or physical problems. Some difficulties were also observed in proper exercise stance for two with Down syndrome, because of short arm length (stretches with arms behind their heads and elbows to knees). Jumping rope was not a good exercise for all participants in the group. Stamina issues and timing problems could be a partial explanation. The jump ropes used were standard 9-foot, lightweight, polyester/rayon mixture with wooden swivel handles. The rope was not heavy enough to accommodate the slow jump rate of speed. Results may have improved with heavier, longer ropes, and more time within the session allocated for jumping rope.

# Study Limitations

Participants and parents taking part in this study may be atypical of adolescents and young adults with cognitive disabilities. They all lived with their parents, as is typical. All participants either attended school or were employed, which may be atypical of individuals with moderate cognitive disabilities. Parents in this group may be more supportive than

most; they have provided access to a broader range of activities and socialization opportunities than is usually experienced.

This research is subject to the following limitations:

- No attempt was made to control the dietary influences on measured physiological variables.
- The third hour of vigorous weekly physical activity was self-reported.
   No other attempt was made to monitor participants' outside activity.
- 3. The study included a small sample with a control group, which should lessen the impact of limitations listed in one and two.

The delimitations of this research are:

- 4. Research participants were volunteers from a purposive, convenience intact group of adolescents and young adults with moderate cognitive disabilities that was organized 10 years ago.
- 5. The 11 intervention participants were 4 female and 7 male adolescents and young adults with moderate cognitive disabilities, between the ages of 14 and 33, who volunteered to participate with informed assent/consent given, and parental informed consent.
- 6. The parents that were voluntarily interviewed were those of the intervention group members who gave informed consent.
- 7. The physiological measurements evaluated were estimates of percentage body fat derived from anthropometric measurements.
- 8. Intervention compliance required that a third hour of weekly individual activity of choice was completed and self-reported by the

participant or parent as proxy and considered accurate.

#### Assumptions

This research was based on the following assumptions:

- 1. It was assumed the self-reported record keeping on food and exercise logs by participants and their parent proxies was accurate.
- It was assumed that self-reported record keeping of steps taken, displayed by pedometer, would be neither accurate nor valid, since parents or proxies did not always accompany the participants.
- It was assumed that any changes in participants' physiological measurements were due to a combination of exercise and healthy nutrition choices.
- 4. It was assumed that the choice to participate in the intervention was self-determined by the participants.
- 5. It was assumed that parent and participant perceptions reported were accurate and reliable.

# Link to Past Research Studies

Health-related fitness was not the focus of most historic weight loss studies for persons with cognitive disabilities. Body composition was rarely included as a variable. Programs of exercise combined with basic health and nutrition education as a self-determined part of daily routines, hold promise for the improvement of health-related fitness in this subset of the population. Weight loss using behavior modification techniques with this populace took center stage in the research arena, although long-term weight loss was seldom shown. Stunkard (1958) noted that obese people (whether disabled or not) often abandon programs and those remaining in treatment often regain their weight. Fox, Rotatori, and Burkhart (1983) concluded that personality and behavior traits (excluding physical condition) do not appear to be unique to individuals with disabilities.

Although lifestyle change combining increased activity and healthy eating was recognized in 1975 as a successful way to reduce obesity in the general population, a paucity of studies examined specific exercise programs in combination with dietary adjustments for individuals with cognitive disabilities. The currently accepted approach to weight control is focused more on health with ideal weight hinging on the level at which health may be impinged. Body size was of interest in studies with persons having cognitive disabilities and success of research strategies was measured by short-term weight loss. Available measures were limited for this population. Many studies were conducted in institutional, rather than community settings and self-determined choice was overshadowed by externally controlled behavior (food and activity). Living arrangement, level of cognitive disability, and gender were shown to influence prevalence of obesity.

Early studies explored the capability of individuals with cognitive disabilities to learn the skills necessary to take part in physical activity interventions. Literature reviewed demonstrated that motor skills,

muscular strength and endurance, flexibility, and cardiovascular endurance can be increased and recreation/leisure pursuits learned by individuals with cognitive disabilities. Many reported studies including physical activity, lacked sufficient procedural information for comparison or replication: (a) duration [time length of session]; (b) frequency [number of days per week with sessions]; (c) intensity [activity measure, such as number of laps swam or heart rate level]; (d) specific activity protocol [warm-up and cool-down activities and exercises for endurance, strength, or aerobic capacity]; and (e) measures of health-related fitness, such as body composition.

Successful weight loss strategies, which hold promise for future research, were identified in literature. Generalizability of conclusions from studies reviewed was limited by: (a) incomplete participant description [such as etiology, living arrangement, and level of functioning]; (b) evolving MR definitions resulted in inconsistencies of the cognitive levels of participants included in studies; (c) insufficient description of intervention procedures; (d) small sample size, which is inherent in studies with this population; (e) infrequent use of control groups; (f) inadequate or lack of follow-up; (g) lack of practical long-term program maintenance or assistance; (h) research conducted mostly outside community settings complicated interventions; and (i) lack of validated height-weight tables or nomograms for use with and by this population [Pitetti, Rimmer, & Fernhall, 1993].

#### Study Conclusions

Significant results from this study generate promise for interventions to efficiently improve health-related fitness in adolescents and young adults with cognitive disabilities. The intervention developed for this study (Healthy Choices), consisted of exercise training, and education in basic nutrition and health concepts. The importance was stressed of choosing to develop a lifestyle that incorporated eating nutritiously and regular vigorous activity. Motivation to take part in this intervention may have been largely for social reasons. Strategies demonstrated by this study as most beneficial for improving and maintaining healthy body composition were: (a) understanding the rationale for making healthy choices; (b) regular participation in strenuous exercise activity [3 times weekly, at least 1 hour per session]; and (c) recognizing the effects of exercise and eating nutritiously. Study follow-up revealed that exercise was the most beneficial strategy for reducing body fat percentage and increasing muscle mass.

Anecdotal data from discussions and interviews, suggested barriers that effected engagement of this sample in healthy lifestyle practices, including lack of: (a) knowledge in areas of basic health and nutrition; (b) specific exercise routines; (c) rationale and effect of participating in health-related activities; (d) opportunities to engage in activities with friends; (e) transportation; (f) attitudes and lowered expectations of others; and (g) control over menus. The effect of parents'

influence on the healthy lifestyle of their offspring with moderate cognitive disabilities, cannot be overlooked. Frequently, parents provided the opportunity to access health programs, both through choice and by transportation. Parents were aware of available activity choices and strongly influenced meal selections (through meal planning, grocery shopping, preparation, or restaurant selection).

### Implications for the Future

Results of this study demonstrated that significant improvements to the body composition of adolescents and young adults with cognitive disabilities were possible, using the Healthy Choice program. The need exists for continued research with individuals experiencing moderate cognitive disabilities, including individuals with syndromes and other clinical diagnoses. Children through adults, from this subset of the population, should be included in studies in order to understand their lifelong health, exercise, and nutrition needs.

### Research Needs

### Research Needs Linked to This Study

Research to cross-validate results of this intervention with a matched group similar to participants, such as the control group, is needed to increase reliability. Systematic research with a larger sample, or additional groups, could add to the reliability and validity of findings. The total effects of this program on the overall health-related fitness of adolescents and young adults with cognitive disabilities should be

explored. Exercise does not commonly affect only one component of health-related fitness. Measurement of all components in one study would enable investigation and description of possible interaction effects. *Human Protection Requirements* 

Research capacity needs to be ensured for the health-related fitness of individuals with cognitive disabilities. The number of investigators trained in MR health and fitness issues needs to be increased. Joint proposals should be solicited for multidisciplinary research, targeting individuals with cognitive disabilities living in the community. Research subject protection (current ethical and legal rules for human research subjects as they relate to persons with cognitive disabilities) should be critically reviewed. Rules should be revised to facilitate participation of these individuals in all types of research, including health, fitness, and clinical trials, with their autonomy, health, and safety ensured. Provisions should be made to facilitate and ensure the involvement of more individuals with cognitive disabilities, their families, advocates, and healthcare providers in research studies. *Related Research Needs* 

Systematic research into obesity interventions, that include strategies adapted from proven methods for persons without disabilities, is imperative. Establishment of an empirically based, standard definition of overweight and obesity, that considers characteristics of individuals with cognitive disabilities, is greatly needed for this population. In recent

years, participants in Special Olympics competitions have increasingly included individuals without MR. Research conclusions drawn by Special Olympics (from samples represented as persons with MR), may be inaccurate with limited generalizability. Data collection forms should include an area to designate athletes' classification (such as MR, learning disabled, or behaviorally disordered), to prevent contamination of their findings. Currently, individuals possessing Down syndrome are identified, due to possibility of atlantoaxial disorder that could prevent certain physical activities.

#### Measures

Accurately measuring the body composition of individuals with cognitive disabilities should be of primary interest to researchers. An appropriate, accurate, standard measure for estimating body fat needs to be developed, empirically tested, validated, and widely distributed (to individuals with cognitive disabilities, parents, medical profession, and educators). Suggested reference formats for percentage body fat estimates in individuals with cognitive disabilities (specific syndromes, etiologies, and other clinical diagnoses) include: (a) BMI table normed on this population, using appropriate variables; and (b) nomograms. Detailed, easily understood measurement procedures and adjustments (such as height) should accompany reference materials (appropriate for individuals with cognitive disabilities, parents, medical professionals, sports and exercise specialists, educators, and other interested persons).

State of the art body density measures (such as hydrostatic weighing, air displacement [Bod Pod], and DEXA) should be used to thoroughly explain body composition in individuals with cognitive disabilities, including syndromes and other clinical diagnoses. The normal ranges of body fat percentage for this populace need to be determined. Correlational studies accepted generalized regression formulas should be conducted. Resting metabolic rates should be included as a dependent variable in future intervention studies, in order to determine and evaluate any effects on aerobic capacity and cardiovascular endurance.

#### Dissemination and Application of Findings

Research findings of health-related fitness studies for persons with cognitive disabilities should be more visible and available beyond the academic community. Findings should be disseminated in accessible, in easily understood formats, perhaps summarized, for professional and lay consumption. Findings from these studies should be used to generate ideas, develop screening tools, educational programs and materials, and to make recommendations and widely distribute them to benefit the target population.

Development of a website containing health-related information focused on the needs of adolescents and young adults with cognitive disabilities should be developed for these individuals, their parents, caretakers, and other concerned persons. The effectiveness of such a

website should be periodically evaluated, with revisions and updates made. Addressing literacy issues, using current technology (such as mouse-cross areas to enable an audible reader function) and included topics of interest, could enhance their ability to use the website. Goal setting and self-monitoring forms could be placed on the site, as well as interactive material (such as an online BMI calculator recalibrated for individuals with cognitive disabilities).

# Health-Related Material

The shortage of appropriate, easy to access health-related curricular and informational materials for this population subset, handicaps their ability to learn and understand basic health, nutrition, exercise concepts, and rationale. It is imperative that this problem be addressed quickly. Development of commercial material and clear communication of its availability could greatly impact lifelong nutritional and activity habits of individuals with cognitive disabilities.

A variety of materials focused on individuals with cognitive disabilities should be developed and include: (a) characteristics [including syndromes, clinical diagnosis, coexisting conditions] and associated issues [such as vision, mobility and spasticity, behavioral differences, and communication problems] across the lifespan; (b) strategies to effectively and efficiently work with this population; (c) modification and adaptation suggestions that would provide access to fitness areas that could improve their health; (d) pre-packaged and all-

inclusive programs; (e) being reasonably priced; (f) accessible workshops and training to implement programs; and (g) being marketed with discipline application, or new niche and community inclusion.

The high illiteracy rate of individuals with cognitive disabilities should be approached using material developed specifically for this population, as well as adaptations of material effective for the general public. Individuals that understand and directly work with this population should be intimately involved in the creation of this material. Information should be factual, produced in brief, simple, colorful, high interest/low readability format, with many related pictures. Use of varied formats (such as exercise cards, self-monitoring aids, audio and video taped information, CDs, DVDs, interactive computer and internet material) would increase its use.

Professionals working with this population should be required to have specific training (such as teacher education programs, medical, sports medicine and exercise workshops or internships working directly with this population). Continuing education should be required. Prepackaged, all-inclusive educational programs that are easily accessible, ready to implement, reasonably priced, and include: (a) hands-on materials; (b) scope and sequence manuals, with defined vocabulary, lesson plans, and related applicable activities and projects; and (c) large pictorial, color graphics (such as flip charts, and wall charts) suitable for large group or one-on-one use.

### Funding

A funding mechanism needs to be developed and implemented, which provides incentive to work with individuals having disabilities; including some payment to health clubs and trainers for health prevention and fitness maintenance in this population. The developmental and implementation costs to society would be much less than the personal and medical costs of obesity associated chronic illnesses. Grant opportunities should be made available to develop and validate model health-related fitness programs and interventions for these individuals. Multidisciplinary input should be encouraged with individuals with cognitive disabilities, having their families working in conjunction. Grant opportunities should be extended beyond schools, universities, and government agencies; they should be available to persons that work closely with members of this population on a regular basis.

### **Final Conclusions**

The difficulties faced by adolescents and young adults with disabilities in the health-related areas of weight loss and exercise were evident. The findings surrounding similar intake of food and eating habits between people of normal weight and those overweight is important. This study demonstrated that the combination of increasing activity levels and better understanding of food types is essential to produce healthier body composition.

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Factors Contributing to Overweight and Obesity

#### APPENDIX A

# FACTORS CONTRIBUTING TO OVERWEIGHT AND OBESITY Overview

The increasing interest in eating disorders, such as obesity and anorexia, is evidenced by the influx of information appearing in scientific literature and popular media. Because of associated health risks, obesity, like anorexia nervosa, is considered a growing problem in the United States and Great Britain, (World Health Organization [WHO], 1998).

Researchers have explored many theories to explain the causes of obesity, which are not listed by rank order:

- 1. lack of exercise
- genetic tendency influenced by environment (Cole, Bellizzi, Flegal, & Dietz, 2000a, 2000b; Craddock, 1978; Thompson, 1993)
- 3. links to specific diseases (Stock & Rothwell, 1982)
- 4. fat distribution abnormalities and obesity associated with cognitive and physical disabilities (Jung, 1991)
- disruptions in fat storage and maintenance (Wooley, Wooley, & Dyrenforth, 1979)
- the role of brown fat or adipose tissue storage mechanisms due to genetic endocrine and metabolic rate (Bjorntorp, 1987; Garrow, 1986)
- 7. specific personality characteristics and traits (Adeyanju, 1990)
- 8. consumption of comfort food as a reaction to stress (Bruch, 1973)

- 9. family variables and related learned food behaviors (Bruch, 1973)
- appetite, hunger, and satiety affected by variables such as palatability, eating styles, and environmental determinants (French, Story, & Jeffrey, 2001; Glanz, Basil, Malbach, Goldberg, 1998; Hill & Peters, 1998)
- 11. inability of to differentiate hunger cues from external sources
- 12. distorted body image

#### *Obesity is Inherited*

Obesity tends to run in families and many obese children tend to become obese adults. Investigations into theories of obesity being attributable to inherited factors have concluded, while genetic factors can make an individual susceptible to weight gain, environment plays an important role in health-related fitness (Craddack, 1978; Cole et al., 2000a, 2000b; Thompson, 1993).

### Nutrition and Eating Habits

Nutrition and eating habits are areas that affect both physical fitness and health. The term *couch potato* was coined by a cartoonist, who satirized the inactive generation with poor health habits (Armstrong, 2003). The couch potato generation continues to sit and snack happily, watching television or playing video games, while obesity numbers and waistlines grow at an alarming epidemic pace (WHO, 1997). Links have been established between food and emotion, and meals play an important role in family life (Bruch, 1973). Dietetic professionals

conducted a survey of 3,000 adults, finding taste to be the most influential factor in food purchase decisions, followed by cost (Glanz et al., 1998). Respondents fell naturally into health-lifestyle clusters, with specific cluster membership predicting the importance of nutrition and weight control on food choices (Glanz et al.). Demographic differences and health-lifestyles predicted consumption of fruits and vegetables, fast foods, cheese, and breakfast cereal (Glanz et al.).

### Fast Food and Convenience Advertised

The most effective food advertising messages stress taste and value (Glanz et al. 1998). Environmental influences that promote obesity through excess energy and fat intake, are: (a) greater availability of fast foods; (b) intense marketing of high-fat, high-taste foods; and (c) larger portion sizes at lower prices (French, Story, & Jeffrey, 2001; Hill & Peters, 1998).

In 1955, the first McDonald's restaurant opened in Illinois and changed the world for busy parents, people who didn't like to cook, and fussy eaters (Jacobson & Fritschner, 1991). The American love affair with the french fry was started, encouraging the same with soft drinks. The per capita soft drink consumption of soft drinks between 1963 and 1990 more than tripled (Jacobson & Fritschner). In response to the high 1980s beef prices, fast food giants were forced to diversify menus, which helped change American diets. Fast food companies considered pork, then added fish and poultry to their staple menu items (fries, beef,

cheese, and soft drinks) (Nations Restaurant News, 1992). To compete for a share of the female market, salads began to appear on fast food menus. The mid 1990s put baked potatoes, along with rollups, and breakfast items on the menus of most fast food chain restaurants (Jacobson & Fritschner).

In the past 80 years, Americans have increased their fat intake about 20%, and sugar consumption almost 40%. Americans also eat more processed foods, which often contained high levels of salt and fat. As fast food giants took taste a step further, fat levels were increased to add distinct flavor touches to traditional foods (such as McDonald's fries cooked in tallow and specialty burgers with secret sauces( (Jacobson & Fritschner, 1991; Nations Restaurant News, 1992). Americans' weights have increased, with three out of five calories consumed as bad fat, or refined sugar. Fresh fruits, vegetables, and fibers (that protect against heart attacks and cancer) have been crowded from our diets (Jacobson & Fritschner; USDHHS, 1996). Poor nutritional habits have been formed for a generation of children raised as fast food junkies, gobbling meals high in fat). After children are hooked, getting parents' business is no problem.

Many people agree that the influx of women into the American workforce was the phenomena that contributed greatly to the success of the fast food industry. America's nutritional habits took a backseat to convenience. Prior to the 1960s, eating out at independent restaurants

that served a variety of homestyle meals was a luxury. More disposable income and less time free time accompanied two family incomes, with a decreased seen in the traditional practice of cooking well-planned meals at home (Jacobson & Fritschner, 1991). Take-out meals purchased appeared to be an efficient use of time and money. American consumers bought into the convenience of the fast food experience, and demand spawned an ever-growing number of corporate fast food chains. Fast food restaurants are somewhat insulated from cyclical inflation and economic downturns, because people always have to eat; their prices are below fine-dining establishments (Sonic Industries, 1989). The 1983 \$1 million television-advertising budget for McDonald's, reached more than \$41 million in 1990 (Advertising Age, 1991).

In deference to some nutrition conscious consumers, many chains have added lower fat choices to their popular high calorie menus that continue to be consumed on a daily basis (Nations Restaurant News, 1996). Many fast food restaurant owners will tell you, "consumers talk low fat and nutrition, but they purchase taste rolled up in high fat, high calorie meal selections" (Sonic Industries, 1994). Consumers do not shop fast food restaurants to make nutritional food choices; evidenced by growing food portion sizes, meal combos sold, and options to super-size (Nations Restaurant News, 1991, 1994, 2002). The popular press recently predicted the current generation might outlive its children for the first time in history (Vieira, 2003).

#### Food Service in Public School

It was estimated that food consumed at school accounted for 35% to 40% of youths' total daily energy intake (Fox, Crepinsek, Connor, & Battaglia, 2001; Dwyer, 1995). In recent years, secondary schools, in particular, have undergone rapid changes in the number and types of foods and beverages available and marketed in schools (Fox et al; Story, Hayes, & Kalina, 1996). The encroachment of fast food and soft drinks into our nation's school cafeterias has contributed to the increased numbers of children, adolescents, and young adults with weight problems (CDC, 2000; Harnack, Stang, & Story, 1999; Ludwig, Peterson, & Gortmaker, 2001; Troiano & Flegal, 1998). In the past two decades, soft drink consumption has increased by 100% among adolescents aged 11 to 17 (Guthrie, & Morton, 2000) and may be contributing to the upward trend in adolescent obesity.

Many school districts experiencing economic crisis, have signed contracts with soft drink companies for marketing fund rebates, positions on lunchtime cafeteria menus for their fast food partners, and vending machine exclusivity in schools (Guthrie & Morton, 2000). Guthrie and Morton noted that more than two-thirds of secondary schools had soft drink contracts providing easy availability to high sugar beverages. Pivotal issues in school food policy discussions and decisions that affect the availability and marketing of food and beverages, include how to fund food service and school activities (Fox et al.; French, Story,

& Fulkerson, 2002; Nestle, 2000, 2002; Wechsler, Brener, Kuester, & Miller, 2001).

Reimbursable school meals offered through the U.S. Department of Agriculture (USDA) National School Lunch Program must meet federally mandated nutrition guidelines (USDA, 1994). Competitive foods, such as a la cart (ALC) and vending machines (VM), do not have to comply with the same standards (Competitive Food Service, 2002). The paucity of ALC and VM food data available, suggests they are higher in fat than foods that are part of school lunch programs (Harnack, Story, Holliday, Lytle, Neumark-Sztainer, 2000; Story, Hayes, & Kalina, 1996; Wechsler, et al., 2001). Wechsler et al.'s study found that most schools offer ALC: (a) 80% served pizza, burgers, or sandwiches; (b) 62% served french fries; and (c) 80% served high-fat cookies or cakes. The same study also found that most schools had vending machines: (a) 95% served soft drinks, candy, or snacks; (b) 90% served fruits and vegetables; (c) 48% served low-fat yogurt, cookies, or pastry; and (d) a few school or district policies included support of more healthful choices for students at school. The study found few descriptive data available on the food environment in schools, influences on adolescents' food choices, or improved planning for more effective school based food interventions.

French, Story, Fulkerson and Gerlach (2003) conducted a two year group-randomized, school-based nutrition trial study, called *Trying Alternative Cafeteria Options in Schools* (TACOS), in 20 Minneapolis-St

Paul and Minnesota metropolitan area schools. The purpose of their study was to increase student purchases of lower-fat foods through student-based, school-wide promotional activities that increased availability of lower-fat foods in ALC and VM areas. Baseline information was gathered in the spring of 2000, before the random selection of schools into experimental conditions. Schools were predominantly in suburban locations with enrollments ranging from 812 to 3,157 students (median=1,731). The student population was 14% non-white (median = 8%, range 3% to 77%), with 9% eligible for free lunches (median = 5%, range 1% to 57%). Food service management companies ran two school district lunch services, with 19 of 20 schools prepared meals on site. All 20 schools participated in the USDA National School Lunch Program. French et al. inventoried the 20-area school ALC menus finding 1,612 individual items offered, with some duplication. Information on school food related policies and practices were obtained from surveys mailed to school principals and food service directors.

Resultant analysis found the largest ALC food-offering category (11.5%) was the chips/crackers category, with 19 schools offering at least one item in this category. This category consisted of the most energy dense items (average kcal/100g = 515), with an average 50% of kilocalories from fat, and few important nutrients. The packaged cookies/bars category, the second densest, had the lowest average price (\$.50 per item, range \$. 10 to \$1.00). The fruits/vegetable category at 17

schools usually included apples, oranges, and bananas, with the second lowest average price (\$.57 per item, range \$.25 to \$2.75). All school menu offerings included nachos with cheese, ice cream/frozen desserts and school prepared high sugar content candy/fruit candy and cookies/bars. The criterion for ALC low-fat foods was 36.4% average fat (range 22.4 to 60.7). Available at all 20 schools were foods in the fruit/candy (97% had 35.4% median fat, meeting TACOS' lower-fat criterion), nonfrozen dairy products, and the bagel and soft pretzel categories. While the fat content of ALC foods was still high, students did alter their purchase habits. The goal was to lower fat consumption and students were making less *bad* food choices.

The CDC (1997) stated that school related-health food and nutrition school practices were inconsistent with national policy and needed increased attention. Researchers inferred that nutrition policy was not given high priority within the secondary school environment, demonstrated by the inconsistency in who took responsibility for setting food policy, the principals or food service directors (Small, Jones, Barrios, et al., 2001; Wechsler et al., 2001).

Literature reviewed suggested that further research should be conducted to examine: (a) the school food environments and dietary quality of food choices that students were exposed to; (b) methods to improve conceptualization and measurement of environmental influences linked to the potential effect of food choices that were high fat or high

sugar foods and beverages; and (c) the effect of beverage funds on student health.

#### Physical Education in Public Schools

Ironically, as the relationship between being overweight or obese and early habits of making poor mealtime and activity choices were explained by the energy balance equation; physical education (PE) programs began to disappear from our public schools (U.S. Surgeon General, 1996). The generation of children without regular PE, with the growing popularity of television and computer games, was directly influenced to adopt sedentary lifestyles (USDHHS, 1996).

PE is concerned with teaching skills and knowledge, that form attitudes through human movement; aiding student development and maintenance of good health practices and community participation (Seaton, Schmottlach, Clayton, Leave, & Messersmith, 1983). The goal of PE curriculum content in motor skill development for traditional students has been to teach effective, comfortable movement for everyday activities, as well as the enjoyment of movement during sports and leisure activities (Snell, 1993).

APPENDIX B

Effects of Poverty on Health-Related Fitness

#### APPENDIX B

#### NUTRITIONAL EFFECTS OF POVERTY

Bhattachatya, Thomas, Haider, and Currie (2003) investigated the effects of poverty on American families during the winter. The study utilized multivariate analysis on data sets contained in two large nationally representative databases: The Consumer Expenditure Survey (CEX) and the third National Health and Nutrition Examination Survey (NHANES III). CEX was a survey with 104,747 households administered by the U.S. Bureau of Labor Statistics conducted from 1980 through 1998. The CEX included long-term household expenditure information on food and other items. NHANES III, administered between 1988 and 1994, provided information on nutrition.

A comparison of American family food expenditures and nutritional outcomes was made for families living at mean or above income levels, and the extent to which parents were able to protect their children from resultant practices. A seasonal food expenditure cycle was identified among America's poor. Impaired intellectual performance associated with mild iron deficiencies was noted, supportive of earlier studies (Bhattachatya et al., 2003; Centers for Disease Control and Prevention [CDC], 1996).

Although actual starvation is rare in the United States, and classic vitamin deficiencies (such as scurvy or pellagra) seldom surface, poor nutritional choices run rampant in America's children. Their diets are

high in fat and sweet intake and low in fruit and vegetable consumption. As result of these poor nutritional choices, American children are experiencing a high prevalence of anemia, high blood cholesterol, and some serum vitamin deficiencies as adolescents (Battacharya & Currie, 2001).

Few studies have suggested that vitamin deficiencies exist in the diets of American children living at or below poverty level (Devaney, Gordon, & Burghardt, 1995; Middleman, Emans, & Cox, 1996). However, the results of Bhattachatya et al.'s (2003) research implied that existing social programs, meant to help poor families endure economic events (such as food stamps, school meal programs, and long-term utility repayment plans), are insufficient to buffer poor families from cold weather shocks. The behavior of America's poor families during cold weather included cutting back on food, which negatively impacted nutrition, in an attempt to balance higher costs associated with efforts to stay reasonably warm. Ability to learn is effected by nutrition, as well as body size and physical fitness. Parental nutrition was worse during the cold months, affecting their psychological state, as they opted to somehow feed their children and keep them from experiencing the effects of extremely cold weather. During these months, ability to work was lowered, and neglect and abuse were higher. Already experiencing significant difficulties related to their impaired lower abilities, many individuals living at or below the poverty level are cognitively impaired.

# APPENDIX C

Closing the GAP Report Goals

ວັ	CLOSING THE GAP PROGRAM GOALS	
	Goals to Support Persons With MR	Action(s)
F	I latestate health acamation to community anyironment	1. Create and implement adjuration programs
-		
		A. persons with MR (self-care and weliness; occupation hazard protection)
		B. parents of persons with MR (care responsibilities)
		C. direct support personnel (DSP) (turnover prevention)
l'`	2 Increase knowledge and understanding of health and MR	1. Community persons concerned with health and MR
	- practical, easy to use	A. Create a national research agenda focusing on health and MR research
		B. identify research priorities and capacity
		C. collect data from protected research participants
		D. understand and use research findings
<u>["</u>	3 Improve healthcare quality	1. Address priority areas for healthcare quality improvement
	•	A. create standards of care
		B. define the role of healthcare practitioners
		<ol><li>Organize and finance healthcare services</li></ol>
		A. quality improvement
		B. recognize excellence in provision of healthcare to persons with MR
17	4 Train healthcare providers in the care of adults and	1. Address basic and specialized training of healthcare MR providers
	children with MR	A. provide continuing education and training for established MR providers
		B. provide interdisciplinary education and training
		C. define provider competencies
~ ا	5 For healthcare programs financed, ensure good healthcare	1. Address relationships among healthcare financing, service packages
	outcomes for adults and children	outcomes and accountability
		A. create definitions of "effective" and related research terms
		B. define organization and financing of healthcare
		C. define access to appropriate packages of services
		D. leverage health dollars for maximum purchasing power
		E. offset specialized costs to healthcare provider
		in extra patient time and other factors
<b>۳</b>	6 Increase sources of healthcare services for adults and children	1. Address the numbers and diversity of trained and experienced healthcare providers
	and ensure that healthcare is easy to access	A. create allied health professionals
		2. Investigate the complexities of accessing healthcare services
		A. provide community-based healthcare
		B. develop supportive services for providers (case management)
		C. provide specialized equipment at clinical sites
		3. Develop system to provide continuity of care across the lifespan
Ż	Note: Goals were summarized from the Surgeon General's report on	Goals were summarized from the Surgeon General's report on the Conference on Health Disparities and Mental Retardation (2002).
	CLOSING THE GAP. A National Blueprint to mprove the Health	leprint to mprove the Health of Persons with Mentel Reterdation (2002).
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Table 36

# APPENDIX C

# APPENDIX D

Indices of Body Size Studies Reviewed

for Individuals with Cognitive Disabilities

Year	Researchers	Pag	е Туре
1970, 19	71 Nordgren	51	Prevalence (skinfolds)
1974	Kreze, Zelina, Juhas, & Garbara	52	Prevalence
1976	Polednak & Auliffe	53	Prevalence (BMI, skinfolds)
1980	Wallen & Roszkowski	54	Prevalence
1982	Fox & Rotatori	54	Prevalence (BMI)
1985	Fox, Hartney, Rotatori, Kurpiers	55	Prevalence
1986	Kelly, Rimmer, & Ness	55	Prevalence (skinfolds & girth)
1988	Cronk, Crocker, Pueschel, Shea,	56	Prevalence
	Zackai, Pickins, & Reid		
1991	Simila & Niskanen	58	Prevalence (BMI)
1992	Bell & Bhate	59	Prevalence (BMI)
1992	Rimmer, Braddock, & Fujiura	60	Prevalence (BMI)
1993	Rimmer, Braddock, & Fujiura	60	Prevalence (%BF regression)
1995	Rimmer, Braddock, & Marks	62	Prevalence (BMI & blood)
1995	Frey & Rimmer	62	Prevalence
1997	Gibson	63	Prevalence (BMI)
1998	Rubin, Rimmer, Chicoine,	64	Prevalence (BMI)
	Braddock, & McGuire		
2003	Harris, Fada, Rosenberg, Jangda,	64	Prevalence (%BF)
	O'Brien, & Gallager		
2003	Marshall, McConkey, & Moore	65	Prevalence (BMI)
2004	Braunschweig, Gomez, Sheean,	66	Cardiovascular (BMI)
	Tomey, Rimmer, & Heller		
1967	Stuart	82	Weight loss - behavior mod
1967	Abramson	83	Weight loss - behavior mod
1970	Wollersheim	83	Weight loss - behavior mod
1979	Stunkard & Penick	84	Weight loss - behavior mod
1968	Harmatz & Lapuc	92	Wt loss - Behavior Therapy
1969	Moore & Crum	93	Wt loss - Behavior Therapy
1971	Upper & Newton	94	Wt loss - Behavior Therapy
1972	Foxx	95	Wt loss - Behavior Therapy
1975	Buford	96	Wt loss - Behav (Ex, Eat, Edu

# APPENDIX D

## TOPIC INDEX OF STUDIES REVIEWED: BODY SIZE

# TOPIC INDEX, CONTINUED, page 2

1975	Foreyt & Parks	98	Wt loss - Behavior Therapy
1975	Joachim & Korboot	99	Wt loss - Behavior Therapy
1977	Joachim	100	Wt loss - Behavior Therapy
1977	Gumaer & Simon	102	Wt loss - Behavior Therapy
1978	Altman, Bondy, & Hirsch	104	Wt loss - Behavior Therapy
1978	Heiman	106	Wt loss - Behavior Therapy
1979	Rotatori & Switzky	108	Wt loss - Behavior Therapy
1979	Rotatori, Fox, & Switzky	109	Wt loss - Behavior Therapy
1979	Rotatori, Parrish, & Freagon	110	Wt loss - Behavior Therapy
1980	Rotatori, Fox, & Switzky, part 1	110	Wt loss - Behavior Therapy
1980	Rotatori, Switzky, & Fox, part 2	111	Wt loss - Behavior Therapy
1980	Rotatori & Fox	112	Wt loss - Behavior Therapy
1982	Fox, Rotatori, Macklin, & Green	113	Wt loss - Behavior Therapy
1982	Jackson & Thorbecke	114	Wt loss - Behavior Therapy
1983	Fox, Burkhart, & Rotatori	115	Wt loss - Behavior Therapy
1984	Fox, Haniotes, & Rotatori	116	Wt loss - Behavior Therapy
1985	Cottrell	117	Wt loss - Behavior Therapy
1985	Fox, Rosenberg, & Rotatori	120	Wt loss - Behav (Ex & parent)
1986	Rotatori, Fox, Matson, Mehta et al.	121	Wt loss - Behavior (Exercise)
1986	Rotatori, Zinkgraf, Matson, & Fox	121	Wt loss - Behavior Therapy
1987	Norvell & Ahern	122	Wt loss - Behavior Therapy
1990	McCarran & Andrasik	123	Wt loss - Behavior Therapy
1997	Schloss & Alper	123	Wt loss - Behavior Therapy
1959	Francis & Rarick	138	Motor skill development
1959	Howe	140	Motor skill development
1970	Rarick, Widdop, & Broadhead	140	Motor skill development
1968	Wagoner	151	Behavior Motor Skill Dev
1969	Solomon	154	Behavior Motor Skill Dev
1974	Huber	154	Behavior Motor Skill Dev
1978	Schack & Ryan	155	Behavior Motor Skill Dev
2002	Sharp, Pitetti, Rogers, Bohlken,	155	Behavior Motor Skill Dev (Ex)
	& Abendroth		
1975	Ross	156	Exercise
1980	Skrobak-Kaczynski, & Vavik	159	Exercise
1984	Haring & Sawey	159	Cardio (Exercise, Eat, Educ)

# TOPIC INDEX, CONTINUED, page 3

1986	Fisher	160	Exercise & Nutrition
1990	Croce	161	Cardio - Exercise
1991	Pitetti & Tan	162	Cardio - Exercise
1999	Frey, McCubbin, Hannigan-Downs,	165	Cardio - Exercise
	Kasser, & Skaggs		
2001	Culphf, O'Connor, & Vanin	166	Cardio - Exercise
2001	Pitetti, Yarmer, & Fernhall	167	Cardiovascular
2003	Kozub	169	Cardiovascular
2004	Pitetti & Fernhall	174	Exercise
1998	Chanias, Reid, & Hooper	176	Meta Analysis- Health-Fitness
1983	Fox, Burkhart, & Rotatori	190	Body Comp (H) Technique
1987	Rimmer, Kelly, & Rosentswieg	190	Body Comp (%BF) Technique
1987	Kelly & Rimmer	193	Body Comp (%BF) Technique
1991	Ovalle, Cole, Climstein, & Dunn	194	Body Comp (H) Technique
1994	Burkett & Phillips	194	Body Comp (%BF) Technique
1998	Felix, McCubbin, & Shaw	196	Bone Density (%BF) - DEXA
2001	Himes	197	Skinfolds too large
2003	Horodyski	198	Body Comp (%BF)

Year	Researchers	Page	Туре
1959	Francis & Rarick	138	Motor skill development
1959	Howe	140	Motor skill development
1967	Abramson	83	Weight loss - behavior mod
1967	Stuart	82	Weight loss - behavior mod
1968	Harmatz & Lapuc	92	Wt loss - Behavior Therapy
1968	Wagoner	151	Behavior Motor Skill Dev
1969	Moore & Crum	93	Wt loss - Behavior Therapy
1969	Solomon	154	Behavior Motor Skill Dev
1970, 71	Nordgren	51	Prevalence (skinfolds)
1970	Rarick, Widdop, & Broadhead	140	Motor skill development
1970	Wollersheim	83	Weight loss - behavior mod
1971	Upper & Newton	94	Wt loss - Behavior Therapy
1972	Foxx	95	Wt loss - Behavior Therapy
1974	Huber	154	Behavior Motor Skill Dev
1974	Kreze, Zelina, Juhas, & Garbara	52	Prevalence
1975	Buford	96	Wt loss - Behav (Ex, Eat, Educ)
1975	Foreyt & Parks	98	Wt loss - Behavior Therapy
1975	Joachim & Korboot	99	Wt loss - Behavior Therapy
1975	Ross	156	Exercise
1976	Polednak & Auliffe	53	Prevalence (BMI, skinfolds)
1977	Gumaer & Simon	102	Wt loss - Behavior Therapy
1977	Joachim	100	Wt loss - Behavior Therapy
1978	Altman, Bondy, & Hirsch	104	Wt loss - Behavior Therapy
1978	Heiman	106	Wt loss - Behavior Therapy
1978	Schack & Ryan	155	Behavior Motor Skill Dev
1979	Rotatori, Fox, & Switzky	109	Wt loss - Behavior Therapy
1979	Rotatori, Parrish, & Freagon	110	Wt loss - Behavior Therapy
1979	Rotatori & Switzky	108	Wt loss - Behavior Therapy
1979	Stunkard & Penick	84	Weight loss - behavior mod
1980	Rotatori & Fox	112	Wt loss - Behavior Therapy
1980	Rotatori, Fox, & Switzky	110	Wt loss - Behavior Therapy
1980	Rotatori, Switzky, & Fox	111	Wt loss - Behavior Therapy
1980	Skrobak-Kaczynski, & Vavik	159	Exercise

## APPENDIX D

CHRONOLOGICAL INDEX OF STUDIES REVIEWED: BODY SIZE

## CHRONOLOGICAL INDEX, CONTINUED, page 2\_\_\_\_\_

1980	Wallen & Roszkowski	54	Prevalence
1982	Fox & Rotatori	54	Prevalence (BMI)
1982	Fox, Rotatori, Macklin, & Green	113	Wt loss - Behavior Therapy
1982	Jackson & Thorbecke	114	Wt loss - Behavior Therapy
1983	Fox, Burkhart, & Rotatori	115	Wt loss - Behavior Therapy
1983	Fox, Burkhart, & Rotatori	190	Body Comp (H) Technique
1984	Fox, Haniotes, & Rotatori	116	Wt loss - Behavior Therapy
1984	Haring & Sawey	159	Ex, Eat, Educ (Cardio)
1985	Cottrell	117	Wt loss - Behavior Therapy
1985	Fox, Hartney, Rotatori, Kurpiers	55	Prevalence
1985	Fox, Rosenberg, & Rotatori	120	Wt loss - Behav (Ex & parer
1986	Kelly, Rimmer, & Ness	55	Prevalence (skinfolds & girth
1986	Fisher	160	Exercise & Nutrition
1986	Rotatori, Fox, Matson, Mehta et al.	121	Wt loss - Behavior (Exercise)
1986	Rotatori, Zinkgraf, Matson, & Fox	121	Wt loss - Behavior Therapy
1987	Kelly & Rimmer	193	Body Comp (%BF) Techniqu
1987	Norvell & Ahern	122	Wt loss - Behavior Therapy
1987	Rimmer, Kelly, & Rosentswieg	190	Body Comp (%BF) Techniqu
1988	Cronk, Crocker, Pueschel, Shea,	56	Prevalence
	Zackai, Pickins, & Reid		
1990	Croce	161	Cardio - Exercise
1990	McCarran & Andrasik	123	Wt loss - Behavior Therapy
1991	Ovalle, Cole, Climstein, & Dunn	194	Body Comp (H) Technique
1991	Pitetti & Tan	162	Cardio - Exercise
1991	Simila & Niskanen	58	Prevalence (BMI)
1992	Bell & Bhate	59	Prevalence (BMI)
1992	Rimmer, Braddock, & Fujiura	60	Prevalence (BMI)
1993	Rimmer, Braddock, & Fujiura	60	Prevalence ( %BF regression
1994	Burkett & Phillips	194	Body Comp (%BF) Techniqu
1995	Frey & Rimmer	62	Prevalence
1995	Rimmer, Braddock, & Marks	62	Prevalence (BMI & blood)
1997	Gibson	63	Prevalence (BMI)
1997	Schloss & Alper	123	Wt loss - Behavior Therapy
1998	Chanias, Reid, & Hooper	176	Meta Analysis Health-Fitnes
1998	Felix, McCubbin, & Shaw	196	Bone Density (%BF) - DEXA

## CHRONOLOGICAL INDEX, CONTINUED, page 3\_\_\_\_\_

1998	Rubin, Rimmer, Chicoine,	64	Prevalence (BMI)
	Braddock, & McGuire		
1999	Frey, McCubbin, Hannigan-Downs,	165	Cardio - Exercise
	Kasser, & Skaggs		
2001	Culphf, O'Connor, & Vanin	166	Cardio - Exercise
2001	Himes	197	Skinfolds too large
2001	Pitetti, Yarmer, & Fernhall	167	Cardiovascular
2002	Sharp, Pitetti, Rogers, Bohlken,	155	Behav Motor Skill Dev (Ex)
	& Abendroth		
2003	Harris, Fada, Rosenberg, Jangda,	64	Prevalence (%BF)
	O'Brien, & Gallager		
2003	Horodyski	198	Body Comp (%BF)
2003	Kozub	169	Cardiovascular
2003	Marshall, McConkey, & Moore	65	Prevalence (BMI)
2004	Braunschweig, Gomez, Sheean,	66	Cardiovascular (BMI)
	Tomey, Rimmer, & Heller		
2004	Pitetti & Fernhall	174	Exercise

APPENDIX	$\mathbf{c}$	
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Year	Researchers	Page	е Туре
1967	Abramson	83	Weight loss - behavior mod
1978	Altman, Bondy, & Hirsch	104	Wt loss - Behavior Therapy
1992	Bell & Bhate	59	Prevalence (BMI)
2004	Braunschweig, Gomez, Sheean,	66	Cardiovascular (BMI)
	Tomey, Rimmer, & Heller		
1975	Buford	96	Wt loss - Behav (Ex, Eat, Educ)
1994	Burkett & Phillips	194	Body Comp (%BF) Technique
1998	Chanias, Reid, & Hoover	176	Meta Health-Fitness
1985	Cottrell	117	Wt loss - Behavior Therapy
1990	Croce	161	Exercise (Cardio)
1988	Cronk, Crocker, Pueschel, Shea,	56	Prevalence
	Zackai, Pickins, & Reid		
2001	Culphf, O'Connor, & Vanin	166	Exercise (Cardio)
1998	Felix, McCubbin, & Shaw	196	Bone Density (%BF) - DEXA
1986	Fisher	160	Exercise & Nutrition
1975	Foreyt & Parks	98	Wt loss - Behavior Therapy
1983	Fox, Burkhart, & Rotatori	192	Body Comp (H) Technique
1983	Fox, Burkhart, & Rotatori	115	Wt loss - Behavior Therapy
1984	Fox, Haniotes, & Rotatori	116	Wt loss - Behavior Therapy
1985	Fox, Hartney, Rotatori, Kurpiers	55	Prevalence
1985	Fox, Rosenberg, & Rotatori	120	Wt loss - Behav (Ex & parent)
1982	Fox & Rotatori	54	Prevalence (BMI)
1982	Fox, Rotatori, Macklin, & Green	113	Wt loss - Behavior Therapy
1972	Foxx	95	Wt loss - Behavior Therapy
1959	Francis & Rarick	138	Motor development
1999	Frey, McCubbin, Hannigan-Downs	s, 165	Cardio - Exercise
	Kasser, & Skaggs		
1995	Frey & Rimmer	62	Prevalence
1997	Gibson	63	Prevalence (BMI)
1977	Gumaer & Simon	102	Wt loss - Behavior Therapy
1984	Haring & Sawey	159	Cardio (Exercise, Eat, Educ)
1968	Harmatz & Lapuc	92	Wt loss - Behavior Therapy
1995 1997 1977 1984	Kasser, & Skaggs Frey & Rimmer Gibson Gumaer & Simon Haring & Sawey	62 63 102 159	Prevalence Prevalence (BMI) Wt loss - Behavior Therapy Cardio (Exercise, Eat, Edu

ALPHABETIC INDEX OF STUDIES REVIEWED: BODY SIZE

## ALPHABETIC INDEX CONTINUED, page 2

	The mount commonly, page	4	
2003	Harris, Fada, Rosenberg, Jangda,	64	Prevalence (%BF)
	O'Brien, & Gallager		
1978	Heiman	106	Wt loss - Behavior Therapy
2001	Himes	197	Skinfolds too large
2003	Horodyski	198	Body Comps (%BF)
1959	Howe	140	Motor development
1974	Huber	154	Behavior Motor Skill Dev
1982	Jackson & Thorbecke	114	Wt loss - Behavior Therapy
1977	Joachim	100	Wt loss - Behavior Therapy
1975	Joachim & Korboot	99	Wt loss - Behavior Therapy
1987	Kelly & Rimmer	193	Body Comp (%BF) Technique
1986	Kelly, Rimmer, & Ness	55	Prevalence (skinfolds & girth)
2003	Kozub	167	Cardiovascular
1974	Kreze, Zelina, Juhas, & Garbara	52	Prevalence
2003	Marshall, McConkey, & Moore	65	Prevalence (BMI)
1990	McCarran & Andrasik	123	Wt loss - Behavior Therapy
1969	Moore & Crum	93	Wt loss - Behavior Therapy
1970, 1971	Nordgren	51	Prevalence (skinfolds)
1987	Norvell & Ahern	122	Wt loss - Behavior Therapy
1991	Ovalle, Cole, Climstein, & Dunn	194	Body Comp (H) Technique
2004	Pitetti & Fernhall	174	Exercise
1991	Pitetti & Tan	162	Exercise (Cardio)
2001	Pitetti, Yarmer, & Fernhall	167	Cardiovascular
1976	Polednak & Auliffe	53	Prevalence (BMI, skinfolds)
1970	Rarick, Widdop, & Broadhead	140	Motor development
1992	Rimmer, Braddock, & Fujiura	60	Prevalence (BMI)
1993	Rimmer, Braddock, & Fujiura	60	Prevalence ( %BF regression)
1995	Rimmer, Braddock, & Marks	62	Prevalence (BMI & blood)
1987	Rimmer, Kelly, & Rosentswieg	190	Body Comp (%BF) Technique
1975	Ross	156	Exercise
1980	Rotatori & Fox	107	Wt loss - Behavior Therapy
1986	Rotatori, Fox, Matson, Mehta et al.	121	Wt loss - Behavior (Exercise)
1980	Rotatori, Fox, & Switzky	106	Wt loss - Behavior Therapy
1979	Rotatori, Fox, & Switzky	109	Wt loss - Behavior Therapy
1979	Rotatori, Parrish, & Freagon	110	Wt loss - Behavior Therapy

## ALPHABETIC INDEX CONTINUED, page 3

	, <b>1</b> 0		
1979	Rotatori & Switzky	108	Wt loss - Behavior Therapy
1980	Rotatori, Switzky, & Fox	111	Wt loss - Behavior Therapy
1986	Rotatori, Zinkgraf, Matson, & Fox	121	Wt loss - Behavior Therapy
1998	Rubin, Rimmer, Chicoine,	64	Prevalence (BMI)
	Braddock, & McGuire		
1978	Schack & Ryan	155	Behavior Motor Skill Dev
1997	Schloss & Alper	123	Wt loss - Behavior Therapy
2002	Sharp, Pitetti, Rogers, Bohlken,	155	Behavior Motor Skill Dev (Ex)
	& Abendroth		
1991	Simila & Niskanen	58	Prevalence (BMI)
1980	Skrobak-Kaczynski, & Vavik	159	Exercise
1969	Solomon	154	Behavior Motor Skill Dev
1967	Stuart	82	Weight loss - behavior mod
1979	Stunkard & Penick	84	Weight loss - behavior mod
1971	Upper & Newton	94	Wt loss - Behavior Therapy
1968	Wagoner	151	Behavior Motor Skill Dev
1980	Wallen & Roszkowski	54	Prevalence
1970	Wollersheim	83	Weight loss - behavior mod

Institutional Review Board Approvals

## IRB Approval - Healthy Choices



December 13, 2002

Ms. Linda L. Arnold 12900 Burlingame Avenue OKC, OK 73120

Dear Ms. Arnold:

The Institutional Review Board-Norman Campus, has reviewed your proposal, "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents and Young Adults with Mild-Moderate Cognitive Disabilities" at the convened meeting on November 22, 2002. The Board found that this research would not constitute a risk to participants beyond those of normal, everyday life except in the area of privacy which is adequately protected by the confidentiality procedures. Therefore, the Board has approved the use of human subjects in this research.

This approval is for a period of 12 months from November 22, 2002, provided that the research procedures are not changed from those described in your approved protocol and attachments. Should you wish to deviate from the described subject procedures, you must notify this office, in writing, noting any changes or revisions in the protocol and/or informed consent document and obtain prior approval from the Board for the changes. A copy of the approved informed consent document is attached for your use.

At the end of the research, you must submit a short report describing your use of human subjects in the research and the results obtained. Should the research extend beyond 12 months, a progress report must be submitted with the request for continuation, and a final report must be submitted at the end of the research.

If data are still being collected after three years, resubmission of the protocol is required.

Should you have any questions, please contact me at 325-4757 or irb@ou.edu.

Sincerely yours,

Steven O'Scan

Steven O'Geary, Ph.D. Director, Human Research Participant Protection Administrative Officer Institutional Review Board – Norman Campus (FWA #00003191)

JSO FY2002-462

cc:

Dr. E. Laurette Taylor, Chair, Institutional Review Board Dr. Kathryn A. Haring, Educational Psychology

1000 Asp Avenue, Suite 314, Norman, Oklahoma 73019-4077 PHONE: (405) 325-4757 FAX: (405) 325-6029

## IRB Approval – Healthy Extend Research, Enlarge Participant Pool



# The University of Oklahoma

OFFICE OF HUMAN RESEARCH PARTICIPANT PROTECTION

February 6, 2004

Ms. Linda L. Arnold 12900 Burlingame Avenue OKC, OK 73120

SUBJECT: "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents and Young Adults with Mild-Moderate Cognitive Disabilities"

Dear Ms. Arnold:

The Institutional Review Board has reviewed and approved the requested revision to the subject protocol.

Please note that this approval is for the protocol and informed consent form initially approved by the Board on December 5, 2002, and the revision included in your request dated February 4, 2004 to include an additional 30 individuals and increasing your maximum number to 40. If you wish to make other changes, you will need to submit a request for revision to this office for review.

If you have any questions, please contact me at 325-8110.

Sincerely yours,

E. Laurette Taylor, Ph.D.

Chair Institutional Review Board - Norman Campus (FWA #00003191)

JSO FY2002-462

cc: Dr. Kathryn A. Haring, Educational Psychology

## **IRB** Approval - Parental Perceptions



# The University of Oklahoma

OFFICE OF RESEARCH ADMINISTRATION

November 8, 2002

Ms. Linda Arnold EDPY ECH 321 CAMPUS MAIL

Dear Ms. Arnold:

The Institutional Review Board-Norman Campus has reviewed your proposal, "Parent Perceptions: Lifestyle Changes Influenced by Exercise/Activity and Nutrition Training for Adolescents and Young Adults with Cognitive Impairments," under the University's expedited review procedures. The Board found that this research would not constitute a risk to participants beyond those of normal, everyday life, except in the area of privacy, which is adequately protected by the confidentiality procedures. Therefore, the Board has approved the use of human subjects in this research.

This approval is for a period of twelve months from November 8, 2002, provided that the research procedures are not changed from those described in your approved protocol and attachments. Should you wish to deviate from the described subject protocol, you must notify this office, in writing, noting any changes or revisions in the protocol and/or informed consent document and obtain prior approval from the Board for the changes. A copy of the approved informed consent document is attached for your use. Please use the form with the IRB approval notation.

At the end of the research, you must submit a short report describing your use of human subjects in the research and the results obtained. Should the research extend beyond 12 months, a progress report must be submitted with the request for continuation, and a final report must be submitted at the end of the research.

If data are still being collected after three years, resubmission of the protocol is required.

Should you have any questions, please contact me at irb(a)ou.edu.

Sincerely,

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Susan Wyatt Scowidk, Ph.D. Director of the Office of Research Administration and Administrative Officer for the Institutional Review Board-Norman Campus (MPA #1146)

SWS:1k FY2003-110

Cc: Dr. E. Laurette Taylor, Chair, Institutional Review Board Dr. Barbara Greene, Educational Psychology

## IRB Approval - Parental Perceptions Extend Research



# The University of Oklahoma

OFFICE OF HUMAN RESEARCH PARTICIPANT PROTECTION

November 7, 2003

Ms. Linda Arnold EDPY ECH 321 CAMPUS MAIL

SUBJECT: "Parent Perceptions: Lifestyle Changes Influenced by Exercise/Activity and Nutrition Training for Adolescents and Young Adults with Cognitive Impairments"

Dear Ms. Arnold:

Thank you for returning your completed progress report for research conducted with human subjects under the abovereferenced protocol. The Board has reviewed and approved your report. Since you indicate the study is continuing, they have extended your approval to continue this research for an additional twelve-month period ending 11/5/2004.

Please note that this approval is for the protocol and informed consent form reviewed by the Board. If you wish to make any changes, you will need to submit a request for change to this office for review.

Sixty days before the expiration of this approval you will receive notice from the IRB secretary that your approval anniversary is approaching along with information you can use to complete your progress report and request an extension of the approval date.

If you have any questions about the approval given your protocol, please contact me at 325-8110.

Sincerely yours,

O'Geory

Steven O'Geary, Ph.D. Director, Human Research Participant Protection Administrative Officer Institutional Review Board-Norman Campus (FWA #00003191)

JSO FY2003-110

cc: Dr. E. Laurette Taylor, Chair, IRB Dr. Barbara Greene, Educational Psychology

## IRB Approval – Parent Perceptions Enlarge Participant Pool



# The University of Oklahoma

OFFICE OF HUMAN RESEARCH PARTICIPANT PROTECTION

November 7, 2003

Ms. Linda Arnold EDPY ECH 321 CAMPUS MAIL

SUBJECT: "Parent Perceptions: Lifestyle Changes Influenced by Exercise/Activity and Nutrition Training for Adolescents and Young Adults with Cognitive Impairments"

Dear Ms. Arnold:

Thank you for returning your completed progress report for research conducted with human subjects under the abovereferenced protocol. The Board has reviewed and approved your report. Since you indicate the study is continuing, they have extended your approval to continue this research for an additional twelve-month period ending 11/5/2004.

Please note that this approval is for the protocol and informed consent form reviewed by the Board. If you wish to make any changes, you will need to submit a request for change to this office for review.

Sixty days before the expiration of this approval you will receive notice from the IRB secretary that your approval anniversary is approaching along with information you can use to complete your progress report and request an extension of the approval date.

If you have any questions about the approval given your protocol, please contact me at 325-8110.

Sincerely yours,

O'Heary

Steven O'Geary, Ph.D. Director, Human Research Participant Protection Administrative Officer Institutional Review Board-Norman Campus (FWA #00003191)

JSO FY2003-110

cc: Dr. E. Laurette Taylor, Chair, IRB Dr. Barbara Greene, Educational Psychology APPENDIX F

Special Olympics Physical

## APPENDIX F

# Special Olympics Physical Form

SPECIAL OLIMPICS			FOR PARTICIPATION
SECT	ION A - ATHLE	ETE INFORMA	TION
thiete Name			
ate of Birth - Month/Day/Year	_//	Age	Sex (circle one) Male / Female
ame of School / Organization			
			M
			Phone
			)
ealth/Medical Insurance Co			Policy #
SECTION	B - HEALTH H	ISTORY INFO	RMATION
ALLERGIES TO MEDICATIONS	SECTION C - / nt, date prescribed and	15 - Kidney probi 16 - Allergies to fa 17 - Sickle cell dis 18 - Severe bone 19 - Emotional/b 20 - Asthma 21 - Dentures/falt 22 - Impoired ma 23 - Wheelchair/ 24 - Other (pleas MEDICATION) number of times per d	sence of testicle lem/Loss of Kidney lood/bug bits secase/trait e/joint problems lee teeth otor ability /walker se specify below} IS day medication needs to be taken.
	thlete's health, his/her cor		ed by a physician before further participation.* * *
			t the athlete have a full radiological exam before he/she may participate.
CHECK: I have reviewed the abov	e health information or	n & examined the athle vould preclude the athle	lete named in the application & certify there lete's participation in Special Olympics.
RESTRICTIONS:			
PHYSICIAN'S NAME (PRINT)	<u> </u>	Pl	hone
PHYSICIAN'S SIGNATURE		-	Date

OFFICIAL SPECIAL OLYMPICS RELEASE FORM
RELEASE TO BE COMPLETED BY ADULT ATHLETE
I, am at least 18 years old and have submitted the Application
for Participation in Special Olympics. I represent and warrant that, to the best of my knowledge and belief, I am physically and mentally able to participate in Special Olympics Activities. I also represent that a licensed physician has reviewed the health information contained in my application and has certified, based on a medical examination, that there is no medical evidence which would preclude me from participating in Special Olympics. I understand that if I have Down Syndrome, I cannot participate in sports or events which by their nature result in hyper- extension, radical flexion or direct pressure on my neck or upper spine unless I and my physician have completed the official "Special Release for Athletes with Atlanto-Axial Instability", available from the Special Olympics Chapter oofice in my state, or I have had a full radiological exam which established the absence of Atlanto-Axial Instability. I am aware that the radiological exam is required before I can participate in Special Olympics, most especially in the following events: equestrian, gymnastics, diving, pentathlon, butterfly stroke, diving starts in swimming, high jump, alpine skiing and soccer. Special Olympics has my permission, both during and anytime after, to use my likeness, name, voice or words in either television, radio, film, newspapers, magazines and other media, and in any form, for the purpose of advertising or communicating the purposes and activities of Special Olympics to take whatever measures are necessary to protect my health and well-being, including, if necessary, hospitalization. I, the athlete named above, have read this paper and fully understand the provisions of the release that I am signing. I understand that by signing this paper, I am saying that I agree to the provisions of this release.
Signature of Adult Athlete Date
Address / City / Zip
I hereby certify that I have reviewed this release with the athlete whose signature appears above. I am satisfied, based on that review, that the athlete understands this release and has agreed to its terms.
Name (print) Relationship
RELEASE TO BE COMPLETED BY PARENT/GUARDIAN OF MINOR ATHLETE I am the parent/guardian of, the minor athlete, on whose behalf I have submitted the Application for Participation in Special Olympics. I hereby represent that the athlete has my permission to
participate in Special Olympics activities. I further represent and warrant that to the best of my knowledge and belief, the athlete is physically and mentally able to participate in Special Olympics. With my approval, a licensed physician has reviewed the health information set forth in the athlete's application and has certified, based on a medical examination, that there is no medical evidence which would preclude the athlete's participation. I understand that if the athlete has Down Syndrome, he/she cannot participate in sports or events which by their nature result in hyper- extension, radical flexion or direct pressure on the neck or upper spine, unless I and a physician have complete the official "Special Release for Athletes with Atlanto-Axial Instability" form, available from the Special Olympics Chapter program in my state, or the athlete has had a full radiological exam establishes the absence of Atlanto-axial Instability. I am aware that the radiological exam is required for participation in any Special Olympics events, especially the following: equestrian, gymnastics, diving, pentathlon, butterfly stroke, diving starts in swimming, high jump, alpine skiing and soccer. In permitting the athlete to participate, I am specifically granting my permission, both during and anytime after, to Special Olympics to use the athlete's likeness, name, voice and words in television, radio, film, newspapers, magazines and other media, and in any form, for the purpose of advertising or communicating the purposes and activities of Special Olympics activities, at a time when I am not those purposes and activities. If a medical emergency should arise during the athlete's participation in any Special Olympics , on my behalf, to take whatever
measures are necessary to ensure that the athlete is provided with any emergency medical treatment, including hospitalization, which Special Olympics deems advisable in order to protect the athlete's health and well-being. I am the parent/guardian of the athlete named in this application and release. I have read and fully understand the provisions of the above release and have explained these provisions to the athlete. Through my signature on this release form, I am agreeing to above provisions on my own behalf and on the behalf of the minor athlete named above. I hereby give my permission for the athlete named above to participate in Special Olympics games, training, recreation programs and physical activity programs.
Signature of Parent / Guardian Date
Address / City / Zip

APPENDIX G

Researcher Created Instruments

## APPENDIX G

## Healthy Choices

## Participant Pre-Study Questionnaire

Na	me		Date	
1.	Do you participate in any exercised swimming) now.			g, bowling, or
2.		me and tell me w <u>When</u>		en you participate. Like/Dislike 
3.	What activity would you like to	try that you have	en't done yet or o	nly do occasionally?
4.	Do you have an exercise progra If so, how often and what exerc Exercise	eises (sit-ups, etc) <u>When</u>	) do you do and h	uration
5.	When you do exercise or activit	ies, do you do th	em alone or with	someone? Who?

6. Do you have anything (weight, muscles, etc.) that you want to try to change with nutrition or exercise?

7. Tell me about your eating habits. What do you like to eat (favorites) and snack on? (favorites).

- 8. Would you and your parent, guardian or aid write down for me for a week, when you exercise and do an activity and what you eat (meals and snacks)?
- 9. How happy are you with your lifestyle now?
- 10. Is there anything else you want to tell me about?

## Participant Post-Study Questionnaire

Name\_\_\_\_\_ Date\_\_\_\_\_

Did you enjoy participating in this exercise/activity and nutrition training program?
 \_\_yes \_\_\_no

2. Which part and activity/exercise did you like the best and which, the least?

3. Did your eating habits change during the program? Will you continue to use the

nutrition training? What part did you like the most and least?

## 4. What things will you continue to do and why?

Exercise/Activity/Nutrition	When	Why

- 5. Do you think this program helped you or not? If so, how? (weight change, muscles, etc.)
- 6. Tell me all the exercises and activities (such as dancing, bowling, or swimming) you did, if alone or with someone, and if you liked them. Were there any you would want to do unified?

<u>Activity</u>	<u>Duration</u>	<u>Like/Dislike</u> <u>Alone?</u>	<u>Unified</u>
			_
			_
			_

- 7. What activity would you like to try that you haven't done yet or only do occasionally?
- 8. Tell me about your eating habits. What do you like to eat (favorites) and snack on (favorites).
- 9. How happy are you now with your lifestyle? Why?
- 10. Is there anything else you want to tell me about?

# Food and Activity Log

Name	Date Started	Date Ended		
Sunday	Breakfast Snack Lunch Snack Dinner Snack		Activity/Exercise	Length/With
Monday	Breakfast Snack Lunch Snack Dinner Snack		Activity/Exercise	Length/With
Tuesday	Breakfast Snack Lunch Snack Dinner Snack		Activity/Exercise	Length/With
Wednesday	Breakfast Snack Lunch Snack Dinner Snack		Activity/Exercise	Length/With
Thursday	Breakfast Snack Lunch Snack Dinner Snack		Activity/Exercise	Length/With
Friday	Breakfast Snack Lunch Snack Dinner Snack		Activity/Exercise	Length/With
Saturday	Breakfast Snack Lunch Snack Dinner Snack		Activity/Exercise	Length/With

# **AVERAGE DAILY FOOD INTAKE**

Please list below any foods you usually eat for:

BREAKFAST:	
	How many X per week do you eat:
FASTFOOD?	_X per week
FAVORITE PLACES:	
RESTAURANTS?	X per week
FAVORITE PLACES:	

## APPENDIX H

Parent Interview Protocol

## APPENDIX H

## Parent Open-Ended Interview Protocol

Parent Perspectives - IRB 03-110

Participant Name:	Date:	

#### Parent Perceptions: Lifestyle Changes Influenced by Exercise/Activity and Nutrition Training for Adolescents and Young Adults with Cognitive Impairments

This study is a companion to the Healthy Choices in Fitness and Nutrition (IRB02-462) that your child will be participating in under the auspices of the University of Oklahoma, Norman Campus. The purpose of this study is to gather information about your perspectives of the effects of activity and nutrition upon the lifestyle of your child.

- 1. Please describe or tell me about your child with disabilities. (prompts: age, disability type, strengths, goals, etc.)
- Describe or explain to me his/her normal weekly exercise/activity regime. (prompts: are exercise/activities sporadic or seasonal, what activities/exercise, done alone or with a group, only as Special Olympic competition events, is the annual level of activity consistent, etc.)
- 3. What are your thoughts about your child's exercise/activity and nutrition plan? (prompts: how regular is participation, does the child choose the activities/exercise, does the school offer alternative programs, etc.)
- 4. Describe lifestyle plans and issues that your child has. (prompts: participates in what exercise/activity programs, coach potato, things done with friends or alone, nutritional habits, etc.)
- 5. Describe the concerns your child has expressed related to exercise or other health issues. (prompts: exercise/activities they would like to try, tried but didn't like, weight problems, toning up, nutritional choices and programs, self-esteem, problems they want to address through exercise, etc.)
- 6. Describe your hopes for your child's future lifestyle. (prompts: future goals, employment, friends, community participation, etc.)

APPENDIX I

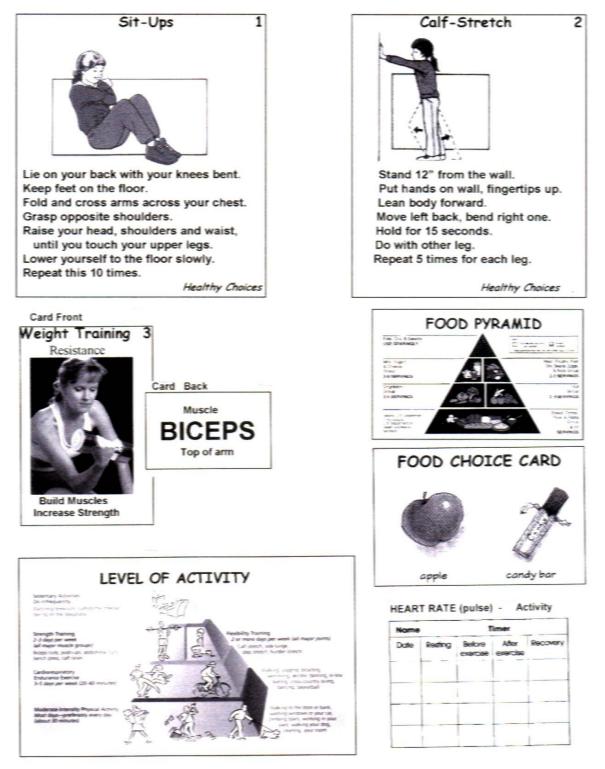
Sample Instruction Information

## APPENDIX I

Sample – Healthy Choices Notebook Picture Sheet

# Before \_\_\_\_\_ After \_\_\_\_\_ **My Measurements** My Measurements Height \_\_\_\_\_ Weight \_\_\_\_\_ Height \_\_\_\_\_ Weight \_\_\_\_\_ Total Inches \_\_\_\_\_ BMI\_\_\_\_ Total Inches \_\_\_\_\_ BMI\_\_\_\_ Notes: Notes:

# See How I Did... "I can make Healthy Choices!"



## Sample Healthy Choices Instruction and Notebook Cards

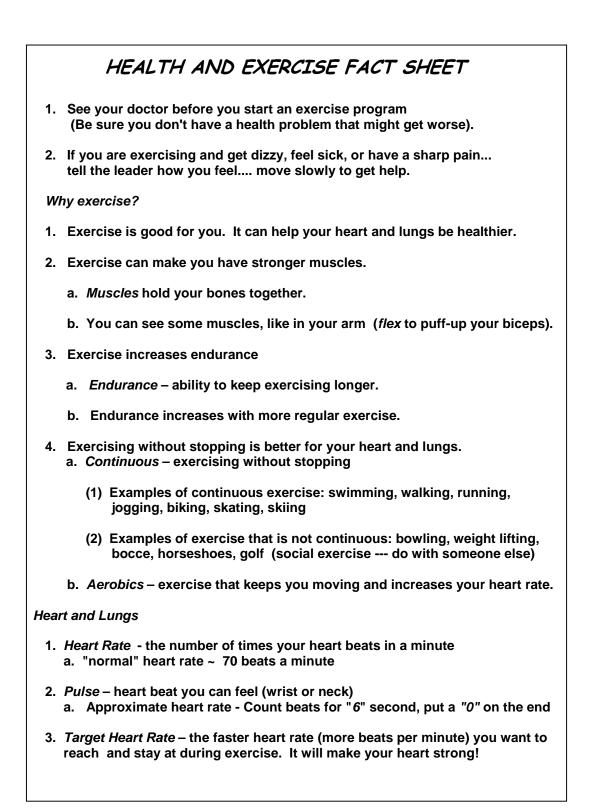
Sample – Health Choices Fact Sheets

# NUTRITION SHEET #1

Drink 8 glasses of water a day (64 ounces) – it keeps your system clean

- Eat in only ONE place.
   a. Example: kitchen table (NOT while watching TV)
- 2. Have plenty of nutritious low calorie foods on hand.
- 3. At meals, take only one serving of food.
- 4. Chew your food completely. Eat slowly. "Enjoy each bite!"
- 5. Drink fewer high-sugar drinks (like pop).
- 6. Eat low calorie snacks, not sugary junk food.
- 7. Make healthy food choices.
  - a. Make fewer bad food choices
    - (1) drink 1 less pop a day (drink 1 water each time you have pop)
    - (2) have fewer unhealthy snacks (have an apple)
    - (3) take the cheese off your burger, or one bun
  - b. Make good choices
    - (1) eat 100 calories less a day
    - (2) eat more fruits and vegetables
    - (3) instead of chips, eat carrots or have popcorn (with no butter)
    - (4) substitute something similar (change it up)

Example: eat frozen yogurt instead of ice-cream have baked instead of fried chips



# EXERCISE TIPS #1

<u>Be active at least 20 minutes a day.</u> Examples: walk the dog, jog, ride your bike, jump rope, run in place, take the stairs instead of the elevator

Walk 100 steps more each day

## EXERCISE PROGRAM FOR FITNESS

- 1. Exercise at least 3 times a week
- 2. Exercise sessions should last at least 25 to 30 minutes
- 3. Wear tennis shoes and loose comfortable clothes

Exercise Sequence

Sequence – order you do exercises in Regimen – the exercises you do doing a session

- 1. Before you start exercising --- Stretch your muscles
  - a. Stretching muscles -- work into positions that slightly stresses
  - b. *Flexibility* -- range of motion around joints
- 2. *Warm Up* start exercising slow and easy

## 3. Exercise Work-Out

Your exercise program. (working with weights and jumping jacks)

- a. Endurance
- b. Strength
- c. Conditioning
- 4. *Cool Down* slowly stop exercising, easily stretch your muscles

														60	ody	Ma	SSE	Inde	Body Mass Index Table	able	03															
			Nor	Normal				ð	Overweight	idht				Obese	۵									<u> </u>	Extreme Obesity	ne O	besi	λ								
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Height (inches)															<u> </u>	Body	Weig	ē I	Body Weight (pounds)	2)	-															
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59	94	66	104	109	114 119		124 1	128	133	138	143	148	153	158	163	168	173	178	183 188		193	198	203	208 2	212 2	217 2	222 23	227 23	232 20	237 24	242 2/	247 25	252 25	257 26	262 26	267
60	97	102	107	107 112 118 123	118		128	133	138	143 148		153	158	153 158 163 168	168	174	179	184	189 194		199	204	209	215 2	220 2	225 2	230 2:	235 24	240 245		250 29	255 26	261 266	6 271		276
61	100	100 106 111 116 122 127	111	116	122		132 1	137	143	143 148 153		158	164	158 164 169 174 180 185	174	180	185	190	195	201	206 2	211	217 3	222 2	227 2	232 2	238 24	243 24	248 29	254 25	259 26	264 26	269 27	275 28	280 28	285
62	104	104 109 115 120 126 131	115	120	126		136	142	147	153	158	164	169	164 169 175 180 186	180		191	196	202	207 2	213	218	224	229 2	235 2	240 2	246 29	251 29	256 26	262 26	267 2	273 27	278 284		289 29	295
63	107	113 118	118	124 1	130 135		141 146		152	158	163	169	175	169 175 180 186	186	191	197	203	208	214 220	220	225	231	237 242		248 2	254 29	259 26	265 2	270 278		282 26	287 29	293 26	299 3(	304
64	110	110 116 122 128	122		134 140		145 1	151	157	163	169	174	174 180 186		. 261	197	204	209	215	221	227	232	238	244 2	250 2	256 24	262 2(	267 2	273 2	279 28	285 29	291 29	296 302		308 37	314
65	114	114 120 126 132 138 144	126	132	138		150 156		162	168	174	180 186	186	192	198	204	210	216	222	228	234 2	240	246	252 2	258 2	264 2	270 2	276 28	282 28	288 29	294 30	300 30	306 312	2 318		324
99	118	118 124 130 136 142 148	130	136	142		155	191	167	173	179	186	192	179 186 192 198 204	204	210	216	223	229	235 2	241	247	253	260 266		272 2	278 284	84 29	291 29	297 30	303 3(	309 31	315 322		328 33	334
67	121	127	134 140	140	146 153		159 1	166	172	178	185	191	198	204	211	217	223	230	236	242 2	249	255	261	268: 2	274 2	280 2	287 29	293 29	299 3(	306 31	312 3	319 32	325 331		338 3,	344
68	125	131	138	131 138 144 151 158	151		164	171	117	184	190	197	203	210	216	223	230	236	243	243 249 256		262	269	276 2	282 2	289 2	295 3(	302 3(	308 3.	315 32	322 32	328 <del>3</del> 2	335 341	11 348		354
69	128	128 135 142 149 155 162	142	149	155		169	176	182	189	196	203	209	216 223	223	230	236	243.	250	257	263	270	112	284 2	291 2	297 3	304 3	311 3.	318 3	324 33	331 33	338 37	345 351	1 358		365
70	132	139 146 153	146	153	160 167		174	181	188	195	202	209	216	222	229	236	243	250	257	264 2	271 2	278	285	292 2	299 3	306 3	313 37	320 32	327 3.	334 34	341 34	348 35	355 36	362 36	369 3	376
11	136	136 143 150 157	150	157	165 172		179 1	186	193	200	208	215	222	229	236	243	250	257	265	272 279	279	286	293	301 3	308 3	315 3	322 3	329 3.	338 3,	343 35	351 39	358 36	365 372		379 36	386
72	140	140 147 154 162	154		169 177		184	161	199	206	213	221	228	235	242	250	258	265	272	279 2	287	294	302	309 3	316 3	324 3	331 3.	338 34	346 3	353 361		368 37	375 38	383 35	390 3	397
73	144	151	151 159 166	166	174 182		189	197	204	212	219	227	235	242	250	257	265	272	280	288	295	302	310	318 3	325 3	333 3	340 3/	348 39	355 3(	363 371		378 36	386 39	393 401		408
74	148	155	163	155 163 171 179 186	. 6/1		194	202	210	218	225	233 241	241	249 256	256	264	272	280	287	287 295 303		311	319	326 3	334 3	342 3	350 31	358 3(	365 3	373 36	381 38	389 36	396 404	14 412		420
75	152	160 168 176	168	176	184 192		200	208	216	224	232	240 248		256	264	272	279	287	295	303	311	319	327	335 3	343 3	351 3	359 36	367 3	375 38	383 36	391 39	399 40	407 415	5 423	3 431	E
76	156	164	172	164 172 180 189 197	189		205 2	213	221	230	238	246	246 254 263		271 279		287	295	304 312		320 328	328	336	344 3	353 3	361 3	369 3	377 385	35	394 402		410 418	18 42	426 435		443
Source: Adapted from Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults. The Evidence Report	Adapteo	1 from C	linical (	Suidelin	es on t	he Iden	tificatic	ж. Еve	Auation	(pue '	Treatm	ant of C	Inerwei	ight and	/ Obesi	ity in A	duits: 7	The Evi	tence f	teport.	1															]

Sample – CDC Standardized BMI Table

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APPENDIX J

Sample Exercise Sequence

## APPENDIX J

## Sample Exercise Session

## Exercise Training

1. Obtain exercise mats and dumbbells at weights assigned and place them on gym floor parameters.

2. Warm-up activities (number of repetitions, rotations, speed, and intensity were increased throughout program). All activities were not used during each session, they were added and rotated according to the program plan.

- a. run laps around the gym floor
- b. backward fast-walk length of gym laps

3. Building exercises

- a. whole gym
  - (1) lunges
  - (2) sumo squats
  - (3) sumo lunges
  - (4) jumping jacks
- b. wall exercises
  - (1) chair sits (two then one-leg rotations)
  - (2) wall push ups
  - (3) toe raises (two then one-leg rotations)
  - (4) calf stretches

3. Mats and Weights were retrieved from the parameter of the gym and participants were positioned over the floor where they could see the certified personal fitness trainer and assistants. Mats and weights were placed in front of each participant.

- a. standing floor exercises
  - (1) jumping jacks
  - (2) weights
    - (a) curls
      - (b) side-arm weight raises
- d. floor mat exercises (mats were unrolled for these with weights placed beside the mats)
  - (1) plank
  - (2) push-ups, modified if needed
  - (3) sit-ups, modified if needed
  - (4) leg raises on back (both and individual)
  - (5) side leg raises (top leg and bottom leg)
  - (1) hammer (without and with weight)
  - (2) curls

## Health Club Sessions

- First Session: Trainers instructed the participants how to use the recumbent bikes (foot adjustments and gauges)
- Getting ready: Participants (brought water and towels) met trainers in the lobby and proceeded up the stairs to the second floor exercise room
- Warm-Up: recumbent bike (began with 15 continuous minutes, ended with 25) Exercise floor: Down stairs immediately following bikes to group exercise room

First session: Mat and weight location included in the first session

Endurance and cardio: step exercises, floor exercises

Strength and conditioning: followed gymnasium sequence

~

APPENDIX K

IRB Approved Forms

## APPENDIX K

Sample Healthy Choices Recruitment Notice

Healthy Choices (IRB 02-462)

## Sample Solicitation/Recruitment Flyer

Dear Michael's Friends Member and Parent:

I am conducting a research project while I continue my education at the University of Oklahoma. I would like for you to take part in this study, if you want to.

The study is about how exercise/activity and nutrition effect your lifestyle. We will be gathering information about your current fitness level, how much you exercise and/or do activities now. We will also find out about your current nutritional habits. We will then do some nutritional choice training and work on learning new activities and exercises while maintaining those you currently participate in. We will work and train hard, just like when we swim, and we will always have lots of FUN! When we finish the study, we'll gather information about what part(s) of the program you will continue, what you liked or didn't like, and about new exercise and activities you might like to try.

We will meet at the Quail Methodist Gym on Penn on (date) and (time). If you want to ask me anything about the study before the meeting, call me on my cell (476-0157) or at home (755-1654). See you soon! Linda

# Healthy Choices – Approved Photography Release

Sample Release to Use Photograph

	raphy Release in Fitness and Nutrition
Participant Permission	
	h of me to be used by the researcher in a nderstand that I will receive no compensation.
Participant	Date
Parent/Guardian Permission	
	my permission for a photograph of my child/war ation or publication of this study. I understand th

## Healthy Choices – Approved Assent

Healthy Choices (IRB 02-462) Part III – INFORMED CONSENT

#### Participant Informed Assent Form University of Oklahoma

#### Introduction

This study "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents and Young Adults With Cognitive Disabilities" is being done with the University of Oklahoma, Norman Campus. My faculty sponsor is Kathryn A. Haring, Ph.D. and Linda Arnold, M.Ed. is the principal investigator. This document will explain my project to you and if you volunteer to take part you must sign this sheet.

#### Purpose of the Study

The purpose of this project is to teach you the tools needed to help make healthy choices about nutrition and exercise/activities that will help you stay physically fit. If you worry about your weight, nutrition and exercise/activity these techniques will aid you in achieving your goal to be thinner and in better physical shape.

#### **Description of the Study**

Over an eleven to twelve week time frame as a voluntary participant you will be taught nutrition basics, instruction in the preparation and selection of tasty healthy snacks, exercise and activities, and methods to set and keep track of fitness goals. Along with other instructors, I will teach you many things that will help you toward the goal of making healthy choices that will help you be physically fit. You will be asked to spend a minimum of two hours per week working with me on this project. You will be asked to fill out an exercise /activity nutrition log and answer some questions at the beginning and end of the study. Participation in this study is completely voluntary and if you don't want to participate there will be no penalty or loss of benefits for you. You may discontinue your participation at any time without penalty. If you don't want to be included in audio tapes, video tapes, or photographs, let me know, there will be no penalty or prejudice. All individual information obtained in the study will be held in strict confidence by the researchers.

#### **Benefits and Risks**

This study holds no foreseeable risks or discomforts to you beyond those present in normal everyday life. Individuals that volunteer to take part in this study will be taught the nutrition basics, goal setting and tracking skills, language, and activities/exercise needed to actively participate in making healthy choices for a fit lifestyle. You will not be paid for participating in this study. If you get hurt your parent or guardian or aid will seek emergency treatment for you. They or their insurance will be responsible for paying for any medical treatment. No liability for medical treatment is assumed by the researcher or the University of Oklahoma. Questions about this research study may be directed to Linda Arnold, M.Ed. at (405)-476-0157 or Kathryn Haring, Ph.D. at (405)-325-5404. If you have questions about your rights as a research participant, call The University of Oklahoma, Office of Research Administration (405)-325-8110 or fax them at (405)-325-6029.

#### Video, Audio or Photos

If videos, audios or photos are made, they will be used for my data collection and small portions may be used for professional education purposes. If this project is published or printed, I will not use your real name.

I agree to permit video taping	yes	no
I agree to permit audio taping	yes	no
I agree to permit photography	ves	no

#### Voluntary Consent to Participate

I hereby agree to participate in the above-described research. I understand that my participation is voluntary and that I may withdraw at any time without penalty or loss of benefits.

Voluntary Participant's Signature

Date APPROVED

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## Health Choices 2 - Extended, Approved Participant Assent

#### Participant Informed Assent Form University of Oklahoma - Norman Campus

This sheet will tell you about my project. It will help you decide if you want to take part in the project. You and your parent or guardian must sign the sheet. Your parent or guardian will be your advocate. An advocate is an adult that makes sure you understand the project and that you really want to do it. They will make sure all your questions are answered before you volunteer.

This study is named "Healthy Choices in Fitness and Nutrition." It will teach you about making good choices when you eat and exercise or do activities that should make you healthier. I am doing this project as part of my school work at the University of Oklahoma in Norman. My teacher, Kathryn Haring, is helping me with this project. If you or your parent, guardian, or advocate have any questions you can call either of us (Linda at 476-0157 or Dr. Haring at 325-5404) or the OU Research Office at 325-8110 or fax them at 325-2373.

The reason I am doing this project is to teach you the important things you need to know to help you make healthy choices about what you eat, exercise, and activities that will help you stay physically fit. If you worry about your weight, this project will teach you how to make a goal to be thinner and in better physical shape and things to do to work toward reaching your goal. This project will least for 11 to 12 weeks and you must agree to work with me or a helper a minimum of 2 hours each week. We will teach you how important it is to make healthy choices that will help you be physically fit. You will be taught about nutrition. We will teach you how to pick tasty healthy snacks and how to make them. We will show you the right way to do different exercises and activities. We will show you how to make goals and ways to keep track of how you are doing. If I share the results with others, I will give you a make believe name or use a number so that no one will know what your name is.

When you start this project, you and your parent or guardian will make a list of the exercises and activities you do now and the food you eat every day for a week. We will ask you to answer some questions at the beginning and end of the study to see how much you are learning about exercise, activity and nutrition. We will also weigh you and take some measurements, so we can make some goals and keep track of your progress. You can only take part in this study if you want to. If you start the study and don't want to finish it, it is all right; just tell me you want to stop.

Taking part in this study won't hurt you. It will just teach you: (1) about making good choices when you eat, (2) how to make some snacks, (3) how to make goals and use graphs to keep track of how you are doing, (4) and some exercises to make you strong, (5) and some fun activities. You will not be paid for being in this study. If you get hurt, your parent or guardian will take you to the doctor and pay for it.

I might take photos, videos, or audios of you during this project and small portions may be used for education purposes. If I present the findings or they are published in a magazine, I won't use your name. I will give you a pretend name or number. Let me know if I can do this by marking the yes or no line.

It is all right to video tape me	yes	no
It is all right to audio tape me	yes	no
It is all right to take my picture	yes	

#### Voluntary Consent to Participate

I want to participate in this research study and I know I can quit at any time and it will be all right. It is all right with my parent(s) or guardian advocate for me to be in this study. We will sign below and they will sign another form also.

Voluntary Participant's Signature

Date



## Healthy Choices \_ Approved Affirmation

Healthy Choices (IRB 02-462)

#### Participant Informed Affirmation Form University of Oklahoma

#### Introduction

This study "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents With Cognitive Disabilities" is being conducted under the auspices of the University of Oklahoma, Norman Campus, Educational Psychology, Special Education Program. The sponsor is Kathryn A. Haring, Ph.D. and Linda Arnold, M.Ed. is the principal investigator. This document serves as an individual consent for participation in this research project.

#### Purpose of the Study

The purpose of this project is to teach you the tools needed to help make healthy choices about nutrition and exercise/activities that will help you stay physically fit. If you worry about your weight, nutrition and exercise/activity are techniques to aid you in achieving your goal to be smaller and more physically fit.

#### **Description of the Study**

Over an eleven to twelve to week time frame voluntary participants will be taught nutrition basics, instruction in the preparation and selection of tasty healthy snacks, exercise and activities, and methods to set and keep track of fitness goals. Along with other instructors, I will teach you many things that will help you toward the goal of making healthy choices that will help you be physically fit. Participation in this study is completely voluntary and refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue your participation at any time without penalty. If audio or photographs are done, you may refuse to allow such without penalty or prejudice. All information obtained in the study will be held in strict confidence and participants will not be named.

#### **Benefits and Risks**

This study holds no foreseeable risks or discomforts to you beyond those present in normal everyday life. Individuals that volunteer to take part in this study will be taught the nutrition basics, goal setting and tracking skills, language, and activities/exercise needed to actively participate in making healthy choices for a fit lifestyle. Questions about this research study may be directed to Linda Arnold, M.Ed. at (405)-476-0157 or Kathryn Haring, Ph.D. at (405)-325-5404. If you have questions about your rights as a research participant, call The University of Oklahoma, Office of Research Administration (405)-325-4754.

#### Audio

If audiotapes or photos are made, they will only be used for my data collection purposes and small segments may be used for professional education purposes.

I agree to permit videotaping	yes	no
I agree to permit audiotaping	yes	no
I agree to permit photography	yes	no

#### **Voluntary Consent to Participate**

I hereby agree to participate in the above-described research. I understand that my participation is voluntary and that I may withdraw at any time without penalty or loss of benefits.

Voluntary Participant's Signature

Date



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## Healthy Choices 2 – Extended Approved Affirmation

#### Participant Informed Consent Form University of Oklahoma -- Norman Campus

#### Introduction

This study "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents With Cognitive Disabilities" is being conducted under the auspices of the University of Oklahoma, Norman Campus. The faculty sponsor is Kathryn A. Haring, Ph.D. and Linda Arnold, M.Ed. is the principal investigator. This document serves as an individual consent for participation in this research project.

#### Purpose of the Study

The purpose of this project is to teach you the tools needed to help make healthy choices about nutrition and exercise/activities that will help you stay physically fit. If you worry about your weight, nutrition and exercise/activity are techniques to aid you in achieving your goal to be smaller and more physically fit.

#### Description of the Study

Over an eleven to twelve to week time frame, for a minimum of two hours per week, voluntary participants will be taught nutrition basics, instruction in the preparation and selection of tasty healthy snacks, exercise and activities, and methods to set and keep track of fitness goals. Along with other instructors, I will teach you many things that will help you toward the goal of making healthy choices that will help you be physically fit. Participation in this study is completely voluntary and refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue your participation at any time without penalty. If audio or photographs are done, you may refuse to allow such without penalty or projudice. All information obtained in the study will be held in strict confidence and participants will not be named. If results are published or presented, other than as a group, a make believe name or code number will be used instead of your real name.

#### **Benefits and Risks**

This study holds no foreseeable risks or discomforts to you beyond those present in normal everyday life. Individuals that volunteer to take part in this study will be taught the nutrition basics, goal setting and tracking skills, language, and activities/exercise needed to actively participate in making healthy choices for a fit lifestyle. Questions about this research study may be directed to Linda Arnold, M.Ed. at (405)-476-0157 or Kathryn Haring, Ph.D. at (405)-325-5404. If you have questions about your rights as a research participant, call the University of Oklahoma Norman-Campus Institutional Review Board, 405-325-8110, or fax them at (405) 325-2373.

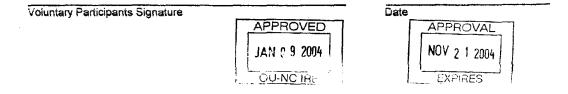
#### Video, Audio or Photos

If videos, audiotapes or photos are made, they will only be used for my data collection purposes and small segments may be used for professional education purposes.

I agree to permit video taping	yes	no
I agree to permit audio taping	yes	no
I agree to permit photography	yes	no

#### Voluntary Consent to Participate

I hereby agree to participate in the above-described research. I understand that my participation is voluntary and that I may withdraw at any time without penalty or loss of benefits.



## Healthy Choices – Approved Parent/Guardian Consent

Healthy Choices (IRB 02-462)

#### Parent or Guardian Permission Form University of Oklahoma

#### Introduction

This study "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents and Young Adults With Cognitive Disabilities" is being conducted under the auspices of the University of Oklahoma, Norman Campus. The faculty sponsor is Kathryn A. Haring, Ph.D. and Linda Arnold, M.Ed. is the principal investigator. This document serves as an individual consent for participation in this research project. You are welcome to join your child in participating in this research project.

#### Purpose of the Study

The purpose of this project is to teach your child the tools needed to help make healthy choices about nutrition and exercise/activities that will help them stay physically fit. If they worry about their weight, nutrition and exercise/activity techniques will aid them in achieving their goal to be thinner and in better physical shape.

#### **Description of the Study**

Over an eleven to twelve week time frame voluntary participants will be taught nutrition basics, instruction in the preparation and selection of tasty healthy snacks, exercise and activities, and methods to set and keep track of fitness goals. Your child will be asked to spend a minimum of two hours per week working with the researcher on this project. Along with other instructors, I will teach your child many things that will help them toward the goal of making healthy choices that will help them be physically fit. Participation in this study is completely voluntary and refusal to participate will involve no penalty or loss of benefits to which you or your child are otherwise entitled. Your child may discontinue their participation at any time without penalty. If audio taping or photographs are done, you may refuse to allow such without penalty or prejudice. All individual information obtained in the study will be held in strict confidence. If results are published or presented in will be done in aggregate or pseudonyms or code numbers used.

#### Benefits and Risks

This study holds no foreseeable risks or discomforts to your child beyond those present in normal everyday life. Individuals that volunteer to take part in this study will spend a minimum of two hours weekly on the project. They will be taught nutrition basics, goal setting and tracking skills, language, and activities/exercise needed to actively participate in making healthy choices for a fit lifestyle. There is no compensation for participating in this study. In the unlikely event that your child would be injured while participating in the study, you will be responsible for seeking medical emergency treatment and assume liability for payment of those charges. No liability for treatment is assumed by the researchers or the University of Oklahoma. Questions about this research study may be directed to Linda Arnold, M.Ed. at (405)-476-0157 or Kathryn Haring, Ph.D. at (405)-325-5404. If you have questions about your rights as a research participant, call The University of Oklahoma, Office of Research Administration (405)-325-8110 or fax them at (405)-325-6029.

#### Video, Audio or Photos

If videos, audios or photos are made, they will only be used for data collection purposes and small segments may be used for professional education purposes. If study results are published or presented it will be done in aggregate or pseudonyms or code numbers used.

I agree to permit video taping	yes	no
I agree to permit audio taping	yes	no
I agree to permit photography	yes	no

#### Voluntary Consent to Participate

I hereby agree for my child to participate in the above-described research. I understand that participation is voluntary and that my child can withdraw at any time without penalty or loss of benefits.

Parent / Guardian of Participant's Signature



## Healthy Choices 2 – Extended - Approved Parent/Guardian Consent

#### Parent or Guardian Permission Form University of Oklahoma

#### Introduction

This study "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents and Young Adults With Cognitive Disabilities" is being conducted under the auspices of the University of Oklahoma, Norman Campus. The faculty sponsor is Kathryn A. Haring, Ph.D. and Linda Arnold, M.Ed. is the principal investigator. This document serves as an individual consent for participation in this research project. You are welcome to join your child in participating in this research project.

#### Purpose of the Study

The purpose of this project is to teach your child the tools needed to help make healthy choices about nutrition and exercise/activities that will help them stay physically fit. If they worry about their weight, nutrition and exercise/activity techniques will aid them in achieving their goal to be thinner and in better physical shape.

#### Description of the Study

Over an eleven to twelve week time frame, for a minimum of two hours per week, voluntary participants will be taught nutrition basics, instruction in the preparation and selection of tasty healthy snacks, exercise and activities, and methods to set and keep track of fitness goals. Your child will be asked to spend a minimum of two hours per week working with the researcher on this project. Along with other instructors, I will teach your child many things that will help them toward the goal of making healthy choices that will help them be physically fit. Participation in this study is completely voluntary and refusal to participate will involve no penalty or loss of benefits to which you or your child are otherwise entitled. Your child may discontinue their participation at any time without penalty. If audio taping or photographs are done, you may refuse to allow such without penalty or prejudice. All individual information obtained in the study will be held in strict confidence. If results are published or presented in other than group form, a make believe name or code number will be randomly assigned by the researcher. Participants will not be named.

#### **Benefits and Risks**

This study holds no foreseeable risks or discomforts to your child beyond those present in normal everyday life. Individuals that volunteer to take part in this study will spend a minimum of two hours weekly on the project. They will be taught nutrition basics, goal setting and tracking skills, language, and activities/exercise needed to actively participate in making healthy choices for a fit lifestyle. There is no compensation for participating in this study. In the unlikely event that your child would be injured while participating in the study, you will be responsible for seeking medical emergency treatment and assume liability for payment of those charges. No liability for treatment is assumed by the researchers or the University of Oklahoma. Questions about this research study may be directed to Linda Arnold, M.Ed. at (405)-476-0157 or Kathryn Haring, Ph.D. at (405)-325-5404. If you have questions about your rights as a research participant, call the University of Oklahoma Norman-Campus Institutional Review Board, 405-325-8110, or fax them at (405) 325-2373.

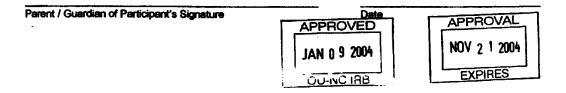
#### Video, Audio or Photos

If videos, audios or photos are made, they will only be used for data collection purposes and small segments may be used for professional education purposes. If study results are published or presented it will be done in aggregate or pseudonyms or code numbers used.

I agree to permit videotaping	yes	no
l agree to permit audio taping	yes	no
I agree to permit photography	yes	no 🕡

#### **Voluntary Consent to Participate**

I hereby agree for my child to participate in the above-described research. I understand that participation is voluntary and that my child can withdraw at any time without penalty or loss of benefits.



## Parental Perceptions Approved Consent

#### Informed Consent: Appendix 1

#### Parent Informed Consent Form University of Oklahoma

#### Introduction

This study entitled Parent Perceptions: Lifestyle Changes Influenced by Exercise/Activity and Nutrition Training for Adolescents and Young Adults with Cognitive Impairments, is to gather information from parents about their perspectives of the effects of activity and nutrition upon the lifestyle of their children with cognitive impairments. The study is a companion to the "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents With Cognitive Disabilities" (IRB02-462) which your child will be participating in. These studies are conducted under the auspices of the University of Oklahoma, Norman Campus. This study is to gather information from parents about their perspectives of the effects of activity and nutrition upon the lifestyle of their children. Barbara Greene, Ph.D. is the faculty sponsor and Linda Amold, M.Ed. is the principal investigator. This document serves as an individual consent for participation in this project.

#### Purpose of the Study

This study is a class project for a graduate degree at the University of Oklahoma. The purpose of the project is to gain information about the perspectives of parents and their children's lifestyle changes after they receive exercise/activities and nutrition training. Many adolescents and young adults with disabilities worry about their weight, nutrition, and social opportunities. With proper training in fitness activities and nutrition, can some of their concerns be ended and their lifestyles enhanced?

#### **Description of the Study**

Over a ten-week period the companion study will give instruction to volunteer adolescents and young adults with cognitive disabilities in nutrition and fitness/exercise activities. Participants of this study are parents of the participants of the companion study. You will be given a questionnaire orally on two occasions that will last for approximately one hour each about your perspectives of the effects of the training on your child. Participation in this study is completely voluntary and refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue your participation at any time without penalty. If audio taping is conducted, you may refuse to allow such without penalty or prejudice. Any information presented or published will be done as an aggregate or by using pseudonyms or code numbers.

#### **Benefits and Risks**

This study holds no foreseeable risks or discomforts to you beyond those present in normal everyday life. Questions about this research study may be directed to Linda Amold, M.Ed. at (405)-476-0157 or Dr. Barbara Greene at (405)-324-1534. If you have any questions about your rights as a research participant, call the University of Oklahoma, Office of Research Administration (405)-325-8110 or fax them at (405)-325-6029

#### Audio Tapes

Audio tapes may be made for data collection purposes and small segments may be used for professional education purposes. Tapes will be erased or destroyed after they are transcribed.

Lagree to permit audio taping \_\_\_\_yes \_\_\_\_no

#### **Voluntary Consent to Participate**

I hereby agree to participate in the above-described research project. I understand that my participation is voluntary and that I may withdraw at any time without penalty or loss of benefits.

Voluntary Participant's Signature

Date



## Parental Perceptions 2 - Approved Consent

#### Parent Informed Consent Form University of Oklahoma

#### Introduction

This study entitled Parent Perceptions: Lifestyle Changes Influenced by Exercise/Activity and Nutrition Training for Adolescents and Young Adults with Cognitive Impairments, is to gather information from parents about their perspectives of the effects of activity and nutrition upon the lifestyle of their children with cognitive impairments. The study is a companion to the "Healthy Choices in Fitness and Nutrition: Lifestyle Changes for Adolescents With Cognitive Disabilities" (IRBO2-462) which your child will be participating in. These studies are conducted under the auspices of the University of Oklahoma, Norman Campus. This study is to gather information from parents about their perspectives of the effects of activity and nutrition upon the lifestyle of their children. Barbara Greene, Ph.D. is the faculty sponsor and Linda Arnold, M.Ed. is the principal investigator. This document serves as an individual consent for participation in this project.

#### **Purpose of the Study**

This study is a class project for a graduate degree at the University of Oklahoma. The purpose of the project is to gain information about the perspectives of parents and their children's lifestyle changes after they receive exercise/activities and nutrition training. Many adolescents and young adults with disabilities worry about their weight, nutrition, and social opportunities. With proper training in fitness activities and nutrition, can some of their concerns be ended and their lifestyles enhanced?

#### Description of the Study

Over a ten-week period the companion study will give instruction to volunteer adolescents and young adults with cognitive disabilities in nutrition and fitness/exercise activities. Participants of this study are parents of the participants of the companion study. You will be given a questionnaire orally on two occasions that will last for approximately one hour each about your perspectives of the effects of the training on your child. Participation in this study is completely voluntary and refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue your participation at any time without penalty. If audio taping is conducted, you may refuse to allow such without penalty or prejudice. Any information presented or published will be done as an aggregate or by using pseudonyms or code numbers.

#### **Benefits and Risks**

This study holds no foreseeable risks or discomforts to you beyond those present in normal everyday life. Questions about this research study may be directed to Linda Arnold, M.Ed. at (405)-476-0157 or Dr. Barbara Greene at (405)-324-1 534. If you have any questions about your rights as a research participant, call the University of Oklahoma-Norman Campus Institutional Review Board (OU-NC IRB) at (405) 325-8110 or fax them at (405) 325-2373.

#### Audio Tapes

Audio tapes may be made for data collection purposes and small segments may be used for professional education purposes. Tapes will be erased or destroyed after they are transcribed.

I agree to permit audio taping \_\_\_\_yes \_\_\_\_no

#### Voluntary Consent to Participate

I hereby agree to participate in the above-described research project. I understand that my participation is voluntary and that I may withdraw at any time without penalty or loss of benefits.

Voluntary Participant's Signature

APPROVED
NOV 0 6 2003
OU-NC IRB



Date