

Behavioral Health in Developmental Disabilities: A Comprehensive Program of Nutrition, Exercise, and Weight Reduction

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We review the literature on the prevalence and conditions resulting in overweight and obesity in people with intellectual disability (ID), followed by obesity treatment research with typically developing children and adaptations for children with ID. In addition to proposing directions for future research and practice, we report a comprehensive randomized control trial (RCT) of family-based behavioral intervention targeting weight loss among adolescents with Down syndrome.

"An epidemic of childhood obesity and overweight, to which social, economic, and human behaviors have contributed, threatens long-term medical, psychosocial, and financial consequences beyond US society's current capacity to respond. How the epidemic is controlled will be about the art and practice of social and behavioral change as well as the art and science of medicine."
(Lavisso-Mourey, 2007, JAMA, 298, p. 920)

The current prevalence rate of obesity among children and adolescents aged 2–19 years is 16.3%; the prevalence rate of overweight is 31.9% (Ogden, Carroll & Flegal, 2008). Children with a body mass index (BMI) for age and gender equal to or above the 95th percentile on the CDC growth charts (CDD, Oct 10, 2008) are considered obese and those with an age-gender specific BMI between the 85th and 94th percentile are considered overweight. Health consequences associated with childhood overweight and obesity include an increased risk of Type 2 diabetes, hypertension, hyperlipidemia, sleep disorders, orthopedic problems and cardiovascular disease, among others (CDC, 2008; Must & Strauss, 1999).

Whereas the trend in childhood and adolescent overweight and obesity increased significantly between 1999 and 2004, fortunately more recent research suggests that it leveled off between 2005 and 2006 (Ogden et al., 2008). It is too soon to know whether the current prevalence rate will remain stable (or perhaps decrease) but what is clear is that unless these rates drop dramatically, the public health toll of obesity will continue to rise as adolescents enter adulthood and begin to suffer the delayed and often life-threatening complications of obesity (Ebbeling & Ludwig, 2008).

Little research has been conducted on the prevalence rates and environmental factors associated with overweight and obesity among children and adolescents with intellectual disabilities (ID), although some research has been conducted with adults. Healthy People 2010, a U.S. Department of Health & Human Services initiative (2000), set forth a framework for national health goals to reduce preventable threats to the nation's health. Obesity and physical inactivity were identified as significant problems facing persons with intellectual disabilities (ID). In 2002, the Surgeon General released "Closing The Gap: A National Blueprint to Improve the Health of Persons With Mental Retardation," a report that highlighted the disparity in health care between persons with ID and the general population. It called for new research and health promotion programmatic efforts to address the health challenges of persons with ID, including obesity (US Department of Health & Human Services, 2002).

The purpose of this paper is to: 1) review selected literature on the prevalence of and conditions affecting overweight and obesity in persons with ID; 2) describe the factors that give rise to the development of overweight and obesity; 3) review a mature body of treatment research on pediatric obesity with typically developing children, particularly on family-based behavioral interventions, which should be replicable, with adaptations, for children with ID; 4) describe a comprehensive randomized controlled trial (RCT) underway investigating a family-based behavioral intervention targeting weight loss with adolescents with Down syndrome (DS); and 5) propose directions for future research and practice using comprehensive behavioral programming.

Overweight and Obesity in Adults and Children with Intellectual Disability

Persons with ID appear to be equally and in some cases more affected by obesity. Rimmer and Yamaki (2006) reviewed the limited extant literature on the prevalence of obesity in adults with ID in and outside of the US, including four studies on four separate cohorts (Lewis, 2002; Harris, 2003; Rimmer & Wang, 2005 and Yamaki, 2005). Overall, the authors found obesity rates similar to those in the general population, with higher prevalences among women, the elderly and persons with DS. Concerning factors associated with increased risk of obesity, there has been significant interest in the role of living environment. Higher rates of obesity have been found among adults with ID who live with their families versus those living in more closely supervised residential settings (Rimmer, Braddock & Fujiura, 1993). Rimmer and Yamaki (2006) report similar results in other studies, pointing to the environmental risks associated with increased independence and poorer diet, and a preference for sedentary activities.

Moran and colleagues conducted a retrospective review of the medical records of 680 adults with ID and 1809 adults without ID in order to determine rates of obesity associated with level of mental retardation, living situation and age (Moran, Drane, McDermott, Dasari, Scurry & Platt, 2005). Results indicated that: 1) the prevalence of obesity was higher among persons with mild versus severe mental retardation and higher than among individuals without ID; 2) persons with ID living in restrictive settings had a lower prevalence of obesity than those living in the less restrictive settings, although this difference faded by age 50 as older individuals in restrictive settings gained weight and "caught up;" 3) there was an increasing trend in obesity throughout the adult lives of individuals with ID; 4) some individuals with ID moved in and out of obesity. The authors suggest that the fourth finding gives hope to health care providers that obesity might be modifiable later in life with intervention.

Research has also shown that adults with DS are highly sedentary (Hoge & Datillo, 1995), with very low levels of physical fitness (Rimmer, Braddock & Marks, 1995; Fernhall & Pitetti, 2001). Rimmer et al. (1995) examined the weight and health status of adults with intellectual disabilities living

independently in the community and found a high prevalence of overweight, obesity, low fitness levels, and other health problems in this population.

There is little information on the natural history of obesity in children with ID. However, children with Prader-Willi syndrome (Holm, Cassidy, Butler, Hanchett, Greenswag, Whitman & Greenberg, 1993) and individuals with Down syndrome (DS) (Bell & Bahte, 1992; Rubin, Rimmer, Chicoine, Braddock & McGuire, 1998) have been reported to have a higher prevalence of overweight than in the general population. Two important determinants of the likelihood of obesity among all children persisting into adulthood are its severity and age of onset. The more severe the level of obesity, the more likely it is to persist; furthermore, the probability of an overweight child becoming an overweight adult increases with age (Guo, Wu, Chumlea & Roche, 2002).

Children and adolescents with ID who learn and practice healthy eating behaviors and engage in regular physical activity at home and in their communities may acquire lifestyle habits that render them less vulnerable to developing obesity during their childhood and adulthood. Research is sorely needed to test this hypothesis, and to investigate interventions to treat weight loss among persons already overweight. Traditional community-based weight loss programs may be difficult to access and participate in for persons with ID, given their limited cognitive abilities and skills. For example, programs such as Weight Watchers require an ability to read, understand and apply complex information such as that contained on nutrition labels and product packages. Further, the group format of such programs may provide few opportunities for individualized teaching and support. These factors, when coupled with the difficulties that the average American citizen has with adopting new lifestyle behaviors, can present significant challenges for individuals with ID to lose weight and engage in new eating and physical activity behaviors – goals that may be unattainable if programs cannot meet their special learning needs.

Factors that give Rise to Obesity

At its simplest, weight gain occurs when an individual's energy (caloric) intake exceeds his or her energy expenditure, which is comprised of their

basal metabolic needs and additional energy expended through physical activity. Eating beyond energy needs appears to be exacerbated by the selection of high energy-dense foods, such as snack foods that are high in fat and sugar. Inactivity, or sedentary behavior, such as TV watching and computer time, further compounds the problem, because less energy is being expended and snacking may be more likely during such activities. Perhaps this analysis suggests that weight gain is primarily a problem of individual restraint. A more comprehensive and contemporary analysis, however, points to the powerful influence of environmental context on behavior. Consider how children and adolescents living at home are influenced by family lifestyle. Parents set examples, or "model" behavior, through their own diet and physical activity habits. They control other key antecedents to eating and exercise as well, such as communicating family goals and priorities with respect to health behaviors, scheduling physical activity, setting rules that limit recreational screen time (TV and computer use), planning and shopping for meals, portioning food at meals, and so on. Parents also provide praise and feedback that can build and strengthen sound diet and physical activity habits. Recognition of the family context has fueled substantial research in family-based behavioral intervention over the last 20 years, which is covered later in this article.

Moving beyond the confines of the family environment, it has become increasingly clear that we live in a media and marketing environment that has been called "obesogenic" and "toxic" (Schwartz & Brownell, 2007). Inexpensive, high-energy-dense foods are available at almost every turn in our communities, with more healthful options harder to find and more expensive. Americans are eating out more frequently, which is also associated with overconsumption of food. In addition, government agriculture subsidies, such as those supporting corn production, have resulted in the inexpensive production of high fructose corn syrup, which is now found in thousands of food products (Pollan, 2006). On the physical activity side of the energy equation, computers and other electronic devices have become widespread and replete with engaging software options to engage children. As suburbs have grown farther and farther from city centers, walking has been replaced by mass transit or reliance on automobiles.

Prevention and Treatment of Obesity in Children with Intellectual Disabilities

The factors described above challenge all families that are trying to live a lifestyle that prevents obesity and promotes lifelong health. Some factors are particularly challenging for persons with ID. Intellectual, social and communication deficits associated with ID may call for more focused teaching and supervision when it comes to practicing positive health behaviors (Modell & Valdez, 2002). Also, children with ID often have poor motor skills (Eichstaedt & Lavay, 1992) which limits opportunities to participate in team sports and other complex physical activities. Lotan, Henderson, and Merrick (2006) noted a lack of trained and knowledgeable personnel available to work with persons with ID, coupled with inadequate facilities and an overly cautious stance taken by many medical professionals. Again, however, because children with ID typically rely on their parents to plan and support physical activity, particularly in the community (Kleinert, Miracle, & Sheppard-Jones, 2007), family-community interventions hold promise. Barriers also exist at the individual and community levels that limit engagement in physical activity, again suggesting that a comprehensive approach to intervention is needed.

Interventions to prevent and treat obesity in persons with ID are sorely needed. These programs will need to be comprehensive if they are to effectively address: 1) the cognitive, behavioral and physical factors associated with intellectual disability; 2) the role of parents and other family members in teaching and reinforcing healthful habits; and 3) the "toxic" environment we live in that makes it particularly difficult to make healthy choices and therefore poses substantial challenges to a healthful transition to independent living for many young adults with ID. Evidenced-based programs are needed that focus broadly on teaching practical knowledge and facilitating associated behavior change toward an enduring lifestyle.

Evidence-Based Behavioral Intervention for Weight Control in Children

A number of theoretical models have been used to guide weight reduction interventions (Baranowski, Cullen, Nicklas, Thompson & Baranowski, 2003),

with social cognitive theory (SCT) viewed as the model most commonly used in educational interventions. Interventions based on SCT frequently incorporate behavior analytic, or “behavior modification” procedures, including monitoring, goal setting, stimulus control (e.g., prompts, schedules, physical environment arrangements), positive reinforcement and behavioral contracting (Robinson, 1999). Research on behavior analytic teaching methods to promote skill development with individuals with ID strongly supports the efficacy of a behavior analytic approach (Cooper, Heron & Heward, 2007), as does research on the roles family members may play in programmatic interventions (Pueschel, 2001). In short, logic suggests that researchers emphasize behavior analytic procedures when attempting to generalize from pediatric weight loss interventions with typically developing children to interventions with children with ID.

Increasingly family-based behavioral interventions have been used to promote weight loss in typically developing children (Young, Northern, Lister, Drummond & O'Brien, 2007; Epstein, Paluch, Roemmich & Beecher, 2007). The potential advantages of involving parents and perhaps siblings include better control of diet at home and when eating out, influence over planning and scheduling of daily activities, including physical activity and grocery shopping trips, and opportunities for frequent supportive interactions. In a meta-analysis of family-based behavioral interventions, results indicated that a family treatment component produced larger effect sizes than alternative treatments (Young et al., 2007). Epstein et al. (2007) employed a mixed-effects regression model to review the very early and most recent literature, with emphasis on the 24-month maintenance of weight loss in the recent studies. Results supported the general efficacy of family-based treatments.

Family-based behavioral weight reduction programs that combine nutrition and physical activity with behavior analytic procedures have been shown to promote weight loss among typically developing children (Epstein, 1996; Epstein, Valoski, Kalarchian & McCurley, 1995; Haddock, Shadish, Klesges & Stein, 1994; Epstein, Valoski, Wing & McCurley, 1990; McLean, Griffin, Toney & Hardeman, 2003). Epstein et al (1990) conducted a 10-year follow-up study with 76 of

their prior research participants (families of typically-developing children) and found that parent participation in behavioral treatment efforts targeting their children, including parent goals for dietary improvements, was an important psychosocial mechanism in effective behavior change and outcomes. Epstein (1996) further emphasized the need for direct and active involvement of at least one parent in child weight reduction, adding that increasing physical activity is important for maintenance of long-term weight control.

Recent research suggests how parents may play a role in promoting sustainable physical activity in their children. Nelson, Gordon-Larsen, Adair and Popkin (2005) applied cluster analysis techniques to analyze data from the National Longitudinal Study of Adolescent Health from 1994-2002. They looked for “meaningful patterns” of physical activity and sedentary behavior to determine what behaviors might be sustained in adulthood. Clusters were used to predict the odds of adolescents and adults meeting national standards for physical activity. Among the top predictors was the cluster adolescents play sports with parent(s); have high frequency of overall sports participation, suggesting a role for parents in influencing physical activity. Also noted was the finding that, in all clusters, bouts of physical activity declined as adolescents approached adulthood, suggesting that interventions to promote maintenance are needed.

McLean, Griffin, Toney and Hardeman (2003) systematically reviewed 16 RCTs of family-based weight reduction interventions that included at least one-year follow up. In the studies involving children, beneficial effects were seen when a comprehensive set of behavior change methods were used, and when both parents and children participated together in learning and applying behavior-change methods. Finally, in a meta-analysis of RCTs of lifestyle-oriented pediatric weight loss treatments (not just family-based), Wilfley, Tibbs, Van Buren, Reach, Walker & Epstein (2007) found support for the short-term efficacy of family interventions, but indicated a need for improvement in long-term effectiveness. In particular the authors pointed to the need to further investigate the procedural dimensions of duration and intensity of interventions.

Health U.: A Comprehensive Weight Loss and Health Promotion Program for Adolescents and Young Adults with Down Syndrome

Health U is a multi-component weight reduction and health promotion program currently being implemented by our research group at the University of Massachusetts Medical School Eunice Kennedy Shriver Center as part of an NIH-funded¹ randomized controlled trial (RCT) comparing nutrition and activity education (NAE) alone to NAE combined with behavioral intervention training for parents. Health U. targets adolescents and young adults ages 13-26 with Down syndrome (DS), and their families. All the participants currently live at home with their families but are in a various stages of transition to an increasingly independent lifestyle; some are in school while others are in supported employment programs or working in competitive jobs in the community. Health U. is based on the extant research on pediatric obesity interventions with typically developing children and adolescents (Young et al., 2007; Wilfley et al., 2007; Epstein et al., 2007), with modifications to meet the participants' cognitive and learning needs. The three major procedural components of Health U. are:

Healthy Eating Plans (HEPs): individualized, prescriptive diet plan for each adolescent

Nutrition and Activity Education (NAE): engaging, hands-on instruction

Behavioral Intervention (BI): parent training in the use of behavior analytic procedures (BI is always implemented in combination with NAE)

Healthy Eating Plans (HEP). Prior to beginning Health U., each participant receives an individualized Healthy Eating Plan (HEP) based on a clinical assessment by a registered dietician that evaluates current diet, typical eating patterns, dietary restrictions, and physical activity. Energy needs are estimated and a balanced diet (USDA food group serving recommendations) is prescribed that seeks a 250-calorie reduction per day, which for most adolescents would result in approximately ½ lb. weight loss per week. The HEPs pictorially represent recommended daily servings for fruits, vegetables, dairy, protein and grains, with personal

discretionary calories for snacks and treats.

Participants are advised to limit treats - high calorie, low nutrient dense foods (e.g., chips, non-diet soda, desserts) to 400 calories per week.

Participants also receive a portion size and food category reference guide. Health U. Classes reinforce HEP goals by encouraging fruit, vegetable and low-fat dairy consumption, replacing fruit juice with actual fruit, drinking water when possible, correct portion sizes, healthy choices (e.g., reducing sweetened beverages, increasing whole grains), and mindful snacking.

Nutrition and Activity Education (NAE). Adolescents and parents attend sixteen 1½ hour classroom sessions in which they are taught about nutrition and healthy eating (8 sessions) and practical physical activity (6 sessions). Two final sessions include a review of the curriculum and a celebratory, healthy potluck dinner. The topics covered in each session are reflected in the titles presented in the left-hand column of Table 1. Nutrition sessions are taught by a registered dietitian and physical activity sessions are taught by an adaptive physical education specialist, each experienced at working with adolescents with ID. Teaching methods minimize lecturing in favor of hands-on activities. Nutrition activities include categorizing food models into bins, preparing and taste-testing healthy snacks, and measuring portions of common foods, among others. All physical activities (e.g., warm-up exercises, walking, stretching, using Therabands© and Theraballs©) are taught via modeling and supervised practice.

In order to standardize the time available for parent-child interactions across the NAE-alone and BI conditions, parents in both groups leave the classroom after the first 45 minutes of each session. Parents in the NAE-alone group meet socially with one another in a small conference room, whereas parents in the BI group meet with a behavior therapist and participate in behavioral intervention training, described below.

¹ NIH R03DK070627-01A2, Fleming (PI), 7/1/06-6/30/08. Parent Supported Weight Reduction in Down Syndrome.

Table 1
Health U. Nutrition & Activity Education (NAE) and Behavioral Intervention (BI) session topics and titles.

S #	Nutrition & Activity Education (NAE)	Behavioral Intervention
1	Good Nutrition and Healthy Eating	Behavior Change!
2	Stay Fit, Stay Strong, Keep Moving all Day Long	Assessing your Environment
3	Fruits, Vegetables and Low-Fat Dairy	Arranging your Environment
4	Getting Ready: Warm-Ups and Stretching	Monitoring and Data Collection
5	Serving Size, Please	Goal Setting I
6	Why is Physical Activity Good for Me?	Goal Setting II
7	Meal Planning I	Reinforcement I
8	Meal Planning II	Reinforcement II
9	Physical Activity at Home and in the Community	Behavioral Contracts I
10	Snack Attack: Healthy Snacking, Mindful Eating	Behavioral Contracts II
11	Physical Activity Strengthening Review	Responding to Challenges
12	Measure Food, Measure Success!	Generalizing Healthy Habits
13	Mindful Physical Activity	Maintaining Behavior Changes
14	Eating Around Town: Eating Out	Fading Support
15	Final Session: Review	Review of Behavioral Intervention
16	Potluck Dinner	Celebration!

Behavioral Intervention (BI). During the second 45 minutes of the each of the NAE sessions, parents in the BI condition meet independently as a group (the adolescents remain in the NAE session) with a Board Certified Behavior Analyst (BCBA) who teaches them to use five behavioral procedures shown to be effective in promoting weight loss in family-based interventions with typically developing children (e.g., Epstein, 1996; Robinson, 1999). Behavioral topics are presented in the right-hand column of Table 1. Procedures, in their order of presentation, include monitoring, stimulus control (arranging the home environment to occasion healthy behaviors, formally scheduling activities, etc.), goal setting, positive reinforcement and behavioral contracting. Each procedure is described in detail below. In each BI session, the BCBA: 1) hands out a weekly insert to a three-ring binder that parents keep, that includes session objectives, learning points, and a homework assignment with instructions and forms; 2) reviews homework and family goals set from the previous session; 3) presents an overview and critical “how-to” information on each new procedure; 4)

engages parents in the discussion and provides consultation on their behavior change efforts at home, including questions and clarifications, barriers they are experiencing, etc.; 5) reviews and clarifies the homework assignment for the upcoming week; 6) assists parents to set diet and activity goals; and 7) confirms the scheduling of a mid-week phone call from the BCBA to discuss interim progress.

An initial parent meeting at the start of the program is used to introduce the behavioral approach to lifestyle change, including its rationale, challenges and component procedures, and to establish the class format. The first procedure taught (Week 2) is monitoring, or daily recording of behavior. “Behaviors” to be monitored by parents and children in collaboration with one another include the number of servings in each of five targeted food categories (grains and cereals, dairy, fruit, vegetable, and high protein) and the frequency and duration of different types of physical activity. Parents are given homework to facilitate monitoring with their child, using two forms. The next procedure taught is stimulus control (Weeks 2-3), which refers to attempts to assess and change

aspects of a family's living environment and activities that either promote or detract from healthy eating and physical activity choices. The associated homework assignment asks parents first to work with their child to conduct observations of events that trigger both healthy and less healthy daily choices aligned with the goals of Health U.

Goal setting is taught in Weeks 3 and 4, and continues throughout the program. Parents are taught to set goals for improvement in observable behaviors, based on prior monitoring, the child's HEP and identified opportunities for physical activity. Goals are required to be logical and challenging, yet realistic and achievable. The BCBA provides significant guidance in assisting parents to choose goals that are specific, clear and attainable. Goal setting is established in this class meeting as a weekly event that continues throughout the entire Health U. program. In fact, in an attempt to firmly establish and strengthen the goal-setting and behavior change relationship, adolescents and parents report publicly on goal achievements at the beginning of each weekly NAE session. Goals accomplished are applauded. Week 5 is used for a review and problem-solving class in which all procedures being used to date are discussed. The next procedure covered is positive reinforcement. Positive reinforcers are relatively immediate events, such as parental praise and affirming feedback, special trips, tangible items, etc., all designed to improve and/or increase the level of ("reinforce") desired behavior, in this case healthy food choices and participation in a range of physical activities.

Behavioral contracting was the final procedure introduced to parents. Behavioral contracts are formal written agreements between two parties that clearly specify what each will do. For example, an adolescent might set a physical activity goal to walk six miles by the end of the week, and the parents might then agree to make a special trip to the movies if the goal is met. Parents were taught to negotiate behavioral contracts with their children and, via homework, to practice and report on contracting over two consecutive one-week periods. The subsequent class reviewed the families' experiences in using all

of the behavioral procedures, and set the stage for two remaining classes on responding to daily challenges (to engaging in healthy eating and physical activity) and systematically maintaining new behaviors as a lifestyle change.

Measurement and Analysis. At the time of this writing Health U. is an ongoing study. Therefore, results comparing weight loss, adherence to dietary recommendations, changes in physical activity, and other indices between groups are not reported. However, it may be helpful to describe some aspects of measurement and data analysis being used in the project as a means of illustrating a comprehensive approach to evaluation that might be used in other research programs, or as a means of evaluating clinical interventions. Because the premise of Health U. is that weight loss should proceed gradually and result from behavior change that is health-promoting and potentially sustainable as a lifestyle change, the following measurements were adopted: height, weight, BMI, percent body fat (Tanita Bioelectrical Impedance Analyzer), physical activity as measured by accelerometry (Actical™ Accelerometers) and food consumption (3-Day Food Records). Height, weight, BMI and body fat are collected prior to each session. Physical activity and food consumption measures are collected over durations of three days and seven days, respectively (participants take 3-Day Food Record and Accelerometers home with detailed instructions) at baseline, 10 weeks, 6 months and 12 months. Pre- and post-tests are taken at baseline and 12 months.

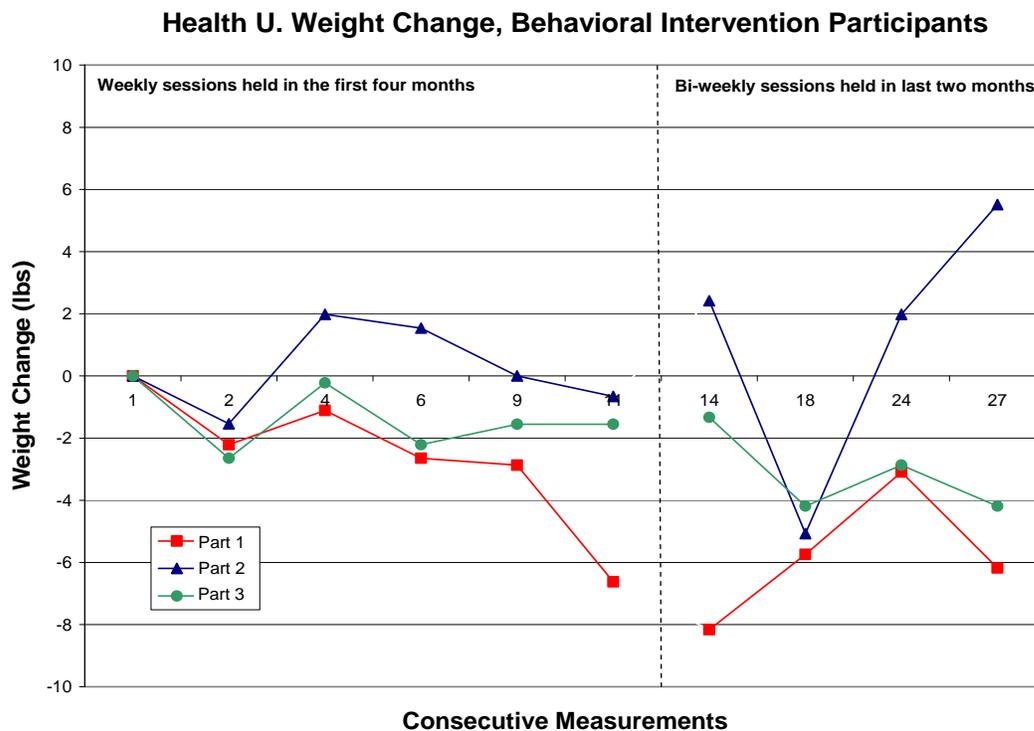
Although too few data have been collected to date to allow for a group comparison, it is interesting at this time to note within-subject variability in weight loss/gain from measurement taken at each session. Figure 1 displays weight change data for three participants with very different response patterns, which times series graphing and analysis of changes in level, trend and variability can help illuminate. Note that Participant 1 shows a steady decrease in weight over the first four months of the intervention, but then a subsequent increase in weight in the final two months as sessions

were spread out to bi-weekly. Participant 2 gained weight initially but returned to just below baseline weight by the end of four months. Weight status over the final two months was highly variable, however. Participant 3 achieved small and gradual weight loss in the first four months, a trend that was sustained in the final two months. These data illustrate how individual variations may vary, and suggest how within-subject analyses might be used in conjunction with RCTs.

balanced diet (adequate micro and macro nutrients) that produces a small daily energy deficit; 2) a nutrition and physical activity education and training approach that minimizes lecture presentations in favor of hands-on activity with guidance, practice and feedback; and 3) a behavioral approach that includes, at the least, the consensus standard components of monitoring, stimulus control, goal-setting, reinforcement.

Research on family-based behavioral interventions with typically developing children has been

Figure 1: Weight change of three participants in the *Health U.* program across a 4-month (10 weekly sessions) period, followed by a 2-month (6 bi-weekly period).



Conclusion and Directions for Research and Practice

A comprehensive approach to prevention and intervention for weight loss/maintenance in persons with ID is needed. Such programs will likely include component procedures previously tested in controlled research with typically developing children and adolescents, but adaptations will be needed to address the cognitive and behavioral needs of children with ID. Component procedures might include those described in the *Health U.* program described in this paper: 1) prescription of an individualized

relatively extensive, and recent reviews have pointed to the need to address long-term maintenance of behavior change. This has long been the case in the behavioral weight-loss intervention research with typically developing adults as well (Wadden, Butryn & Byrne, 2004; Svetkey, Stevens, Brantley, Appel, Hollis & Loria, 2008), and it may prove to be the most important challenge facing parents of children with ID who strive to have their adolescent enter the transition to adulthood with well-established health habits. Suggestions for improving the sustainability of healthful behavior change and desired weight status in children and adults alike has included

increasing the number of treatment sessions and the duration of the intervention period (e.g., to 24 months).

There has also been a call for interventions that investigate systematic social support. Parents, teachers and peers could: 1) serve as coaches, continuing to teach new information; 2) encourage sustained effort, via goal setting, scheduled exercise sessions, etc.; and 3) reinforce maintained skills. For example, Ward, Smith, and Makasci (1997) used directed rehearsal and error correction procedures to successfully teach six preschool physical education teachers to tutor children to increase physical activity. A similar procedure could be employed in research with parents, and targeting diet-related behaviors.

In sum, obesity represents a long-term health risk for persons young and old with ID. The scientific evidence supporting comprehensive behavioral intervention approaches to weight reduction in typical children and adults provides a model for application in the ID population. Our ongoing Health U. RCT eventually will provide data on the efficacy of a multi-component model for treating overweight and obesity in adolescents and young adults with Down syndrome.

References

- Baranowski, T., Cullen, K.W., Nicklas, T., Thompson, D., & Baranowski, J. (2003). Are current health behavioral change models helpful in guiding prevention of weight gain efforts? *Obesity Research*, 11, 235-435.
- Bell, A.J., & Bhate, M.S. (1992). Prevalence of overweight and obesity in Down's syndrome and other mentally handicapped adults living in the community. *Journal of Intellectual Disability Research*, 36(4), 359-364.
- Centers for Disease Control and Prevention [CDC], National Center for Health Statistics (NCHS). (2008). *Clinical growth charts*. Retrieved October 10, 2008 from http://www.cdc.gov/nchs/about/major/nhanes/growthcharts/clinical_charts.htm
- Cooper, J.O., Heron, T.E., & Heward, W.L. (2007). *Applied Behavior Analysis* (2nd ed.). New York: Macmillan
- Ebbeling, C.B., & Ludwig, D.S. (2008). Tracking pediatric obesity: An index of uncertainty? *Journal of the American Medical Association*, 299(20), 2442-2443.
- Eichstaedt, C. B., & Lavay, B. (1992). *Physical activity for persons with mental retardation: Infant to adult*. Champaign, IL: Human Kinetics.
- Epstein, L.H. (1996). Family-based behavioral intervention for obese children. *International Journal of Obesity and Related Metabolic Disorders*, 20(1), S14-21.
- Epstein, L.H., Paluch, R.A., Roemmich, J.N., & Beecher, M.D. (2007). Family-based obesity treatment, then and now: Twenty-five years of pediatric obesity treatment. *Health Psychology*, 26(4), 381-391.
- Epstein, L.H., Vaolski, A.M., Kalarchian, M.A. & McCurley, J. (1995). Do children lose and maintain weight easier than adults: A comparison of child and parent weight changes from six months to ten years. *Obesity Research*, 3(5), 411-417.
- Epstein, L.H., Valoski, A.M., Wing, R.R., & McCurley, M.A. (1990). Ten year follow-up of behavioral, family-based treatment for obese children. *Journal of the American Medical Association*, 264(19), 2519-2523.
- Fernhall, B., & Pitetti, K.H. (2001) Limitations to physical work capacity in individuals with mental retardation. *Clinical Exercise Physiology*, 3, 176-185.
- Guo, S.S., Wu, W., Chumlea, W.C., & Roche, A.F. (2002). Predicting overweight and obesity in adulthood from body mass index values in childhood and adolescence. *American Journal of Clinical Nutrition*, 76(3), 653-8.
- Haddock, C.K., Shadish, W.R., Klesges, R.C., & Stein, R.J. (1994) Treatments of childhood and adolescent obesity. *Annals of Behavioral Medicine*, 16, 235-244
- Harris, N., Rosenberg, A., Jangda, S., O'Brien, K., & Gallagher, M.L. (2003). Prevalence of obesity in International Special Olympic athletes as determined by body mass index. *Journal of the American Dietetic Association*, 103(2), 235-237.
- Hoge, G., & Dattilo, J. (1995). Recreation participation of adults with and without mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 30, 283-298.
- Holm, V.A., Cassidy, S.B., Butler, M.G., Hanchett, J.M., Greenswag, L.R., Whitman, B.Y., & Greenberg, F. (1993). Prader-Willi syndrome: Consensus diagnostic criteria. *Pediatrics*, 91(2), 398-402.
- Jackson, D.M., Reilly, J.J., Kelly, L.A., Montgomery, C., Grant, S., Paton, J.Y. (2003). Objectively measured physical activity in a representative sample of 3- to 4-year-old children. *Obesity Research*, 11, 420-425.
- Kleinert, H.L., Miracle, S., & Sheppard-Jones, K. (2007). Including students with moderate and severe intellectual disabilities in school extracurricular and community recreation activities. *Intellectual and Developmental Disabilities*, 45(1), 46-55.
- Lavizzo-Mourey, R. (2007). Childhood obesity: What it means for physicians. *Journal of the American Medical Association*, 298(8), 920-922.
- Lewis, M.A., Lewis, C.E., Leake, B., King, B.H., & Lindemann, R. (2002). The quality of health care for adults with developmental disabilities. *Public Health Report*, 117, 174-184.
- Lotan, M., Henderson, C.M., & Merrick, J. (2006). Physical activity for adolescents with intellectual disability. *Minerva Pediatrica*, 58(3), 219-226.
- McLean, N., Griffin, S., Toney, K., & Hardeman, W. (2003). Family involvement in weight control, weight management and weight-loss interventions: A systematic review of randomized trials. *International Journal of Obesity and Related Metabolic Disorders*, 27(9), 987-1005.
- Modell, S. J. & Valdez, L. A. (2002). Beyond Bowling: Transitional planning for students with disabilities. *Teaching Exceptional Children*, 34(6), 32-38.
- Moran, R., Drane, W., McDermott, S., Dasari, S., Scurry, J.B., Platt, T. (2005). Obesity among people with and without mental retardation across adulthood, *Obesity Research*, 13(2), 348-351.
- Must, A. & Strauss, R.S. (1999). Risks and consequences of childhood and adolescent obesity. *International Journal of Obesity*, 23(Suppl), S2-S11.

- Nelson, M.C., Gordon-Larsen, P., Adair, L., & Popkin, B. (2005). Adolescent physical activity and sedentary behavior. *American Journal of Preventive Medicine*, 28(3), 259-266.
- Odgen, C.L., Carroll, M.D., & Flegal, K.M. (2008). High body mass index for age among US children and adolescents, 2003-2006. *Journal of the American Medical Association*, 299(20), 2401-2405.
- Pollan, M. (2006). *The omnivore's dilemma: A natural history of four meals*. New York: Penguin Press.
- Pueschel, S.M. (2001). Young people with Down syndrome: Transition from childhood to adulthood. *Mental Retardation and Developmental Disabilities*, 2(2), 90-95.
- Rimmer, J.H., Braddock, D., & Fujjura, G. (1993). Prevalence of obesity in adults with mental retardation: Implications for health promotion and disease prevention. *Mental Retardation*, 31(2), 105-110.
- Rimmer, J.H., Braddock, D., & Marks, B. (1995). Health characteristics and behaviors of adults with mental retardation residing in three living arrangements. *Research in Developmental Disabilities*, 16, 489-499.
- Rimmer, J.H., & Wang, E. (2005). Obesity prevalence among a group of Chicago residents with disabilities. *Archives of Physical Medicine and Rehabilitation*, 86(7), 1461-1464.
- Rimmer, J.H., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 22-27.
- Robinson, T.M. (1999). Behavioural treatment of childhood and adolescent obesity. *International Journal of Obesity*, 28(2), S52-S57.
- Rubin, S.S., Rimmer, J.H., Chicoine, B., Braddock, D., & McGuire, D.E. (1998). Overweight prevalence in persons with Down syndrome. *Mental Retardation*, 36(3), 175-181.
- Schwartz, M.B., & Brownell, K. (2007). Actions necessary to prevent childhood obesity: Creating the climate for change. *Journal of Law, Medicine and Ethics*, 31(5), 78-89.
- Svetkey, L.P., Stevens, V.J., Brantley, P.J., Appel, L.J., Hollis, J.F., & Loria, C.M. (2008). Comparison of strategies for sustaining weight loss: The Weight Loss Maintenance Randomized Controlled Trial. *Journal of American Medical Association*, 299(10), 1139-1148.
- U.S. Department of Health and Human Services (2000). *Healthy people 2010: Understanding and improving health (2nd ed.)*. Washington, DC: U.S. Government Printing Office.
- U.S. Department of Health and Human Services (2001). *Closing the gap: A national blueprint for improving the health of individuals with mental retardation*. Report of the Surgeon General's Conference on health disparities and mental retardation. Washington, D.C.
- Wadden, T.A., Butryn, M.L. & Byrne, K.J. (2004). Efficacy of lifestyle modification for long-term weight control. *Obesity Research*, 12(Suppl), 151S-162S.
- Ward, P., Smith, S. and Makasci, K. (1997). Teacher training: Effects of directed rehearsal on the teaching skills of physical education majors. *Journal of Behavioral Education*, 7(4), 505-517.
- Wilfley, D.E., Tibbs, T.L, Van Buren,, D.J., Reach, K.P., Walker, M.S., & Epstein, L.H. (2007). Lifestyle interventions in the treatment of childhood overweight: A meta-analytic review of randomized controlled trials. *Health Psychology*, 26(5), 521-532.
- Yamaki, K. (2005). Body weight status among adults with intellectual disability in the community. *Mental Retardation*, 43, 1-10.
- Young, K.M., Northern, J.J., Lister, K.M., Drummond, J.A., & O'Brien, W.H. (2007). A meta-analysis of family-behavioral weight-loss treatments for children. *Clinical Psychology Review*, 27, 240-249.

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