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# Obesity and Individuals with Intellectual and Developmental Disabilities

## A Research to Policy Brief

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Obesity is an increasingly common condition that is characterized by an increase in the number and size of fat cells in the body. Obesity is most commonly measured by Body Mass Index (BMI), with a BMI ranging from 25-29.9 kilograms per meter squared (kg/m<sup>2</sup>) indicating an individual is overweight, and a rate greater than 30 kg/m<sup>2</sup> indicating a state of obesity. Rates of overweight and obesity among child and adult populations are an increasing healthcare concern. The number of individuals who are overweight or obese has increased over the past 40 years [1]. This has resulted in an increased focus, understanding, and action for obesity treatment.

Obesity rates are a concern for the general population, but research findings consistently report even higher rates of obesity among individuals with intellectual and developmental disabilities (IDD). The Centers for Disease Control and Prevention report approximately 35% of the general population is obese, while the rate of obesity among adults with IDD is as high as 58.5% in the United States [2-5]. The consequences of obesity predispose adults with IDD to a greater risk of secondary health conditions that can impair their health status and quality of life. In addition, individuals with IDD may possess non-modifiable risk factors for obesity, such as mobility limitations or factors related to the individual's diagnosis. Secondary risk factors, such as barriers to physical activity, lack of social support, higher levels of food insecurity, limited access to proper nutrition, medications that may influence weight, and transportation, may also increase susceptibility to obesity for a child or adult with IDD [2, 6]. In total, obesity is a complex, multi-faceted condition that needs greater attention in the IDD population. The 2005 Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities emphasizes equal opportunities for healthy living for individuals with disabilities. This policy brief will highlight known issues related to obesity in general, issues uniquely related to obesity for individuals with IDD, and provide recommendations and resources for addressing these issues.

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## Research Findings

In 2013, the American Medical Association officially recognized obesity as a disease. Classification of obesity as a disease brings awareness to the need for healthcare coverage and legislation targeted at weight management. Proper treatment of obesity should consider multiple behavioral and biological approaches. Currently, behavioral recommendations for reduced energy intake accompanied by increased energy expenditure are still a primary method for influencing an individual's weight. Numerous behavioral resources designed to assist with weight management and health behaviors exist, but few have been designed specifically for individuals with IDD. Gaps remain between recommended behavioral weight management practice and reported weight management strategies for individuals with IDD [7]. Limited studies utilized a multicomponent weight management approach of dietary restriction, increased physical activity, and behavioral motivation. Other weight loss efforts utilize an electronic based intervention that included weekly sessions with a health educator, electronic diet tools, parent involvement, and encouragement to meet physical activity goals [8]. There are psychosocial benefits from community-based physical activity and exercise programs for adults with IDD. Though some increase in activity has been reported with physical activity interventions, there is a similar lack of comprehensive interventions designed for physical activity promotion for individuals with IDD [9]. When physical activity programs included nutrition information, evidence for weight loss was observed [9].

Considering this, there is a need for multi-component weight management interventions for individuals with IDD. Future interventions should include the same rigors as behavioral weight management interventions assessed with the general population while also providing adaptations for individuals with IDD. Individuals with IDD may also need additional assistance addressing behavioral strategies to promote health-related behaviors, particularly related to social support, nutrition, and physical activity. Weight management interventions for individuals with IDD must adapt to the unique challenges of the IDD population and employ multi-component/multi-level weight management techniques.

## Behavioral Weight Management Resources for People with IDD

Despite the limited amount of research in weight loss interventions for individuals with IDD, there are growing efforts and existing resources to address some of the issues associated with weight gain. These interventions may serve as guidelines for obesity and weight management strategies for individuals with IDD. The following information includes a non-exhaustive list of potential resources related to health behavior and weight management for the caregiver and/or individual with IDD.

### General Health and Wellness

Weight management for people with IDD may affect a number of other health related issues. It is important to obtain assessment of overall health status. The Arc provides free community-based health assessments through its HealthMeet program, which includes exercise and nutrition recommendations. Additional information on assessments, resources, and partnerships are found on The Arc's website, linked below. In addition, a primary healthcare provider can provide individualized information.

## Provider Resources

One evidence-based resource for providers to individuals with IDD is the Health Matters Program. The Health Matters Program is a training and education resource that organizations and communities can reference to identify needs and implement health behaviors to promote the health of individuals with IDD [10]. Included in this is the HealthMatters Initiative, which leverages both the evidence-based "HealthMatters Train the Trainer Program for Instructors" and "12-Week HealthMatters Program for People with IDD" to create health-friendly services through collaborative efforts between UIC, community-based organizations (CBOs), and state fiscal/ policy stakeholders. HealthMatters Initiative aims to achieve widespread transformation of policy, fiscal budgets, and services to support health promotion for people with IDD and their caregivers across three levels within six enrolled states (Alaska, Illinois, Kentucky, Maryland, Missouri, and North Carolina). These goals include, fiscal and policy capacity supporting health and wellness (e.g. CBOs, local communities, states); community and organizational capacity for Health-Friendly Services; and, attainment of health goals and improved health status among people with IDD where they live, learn, work, and play.

Another available resource is The Hennepin County Human Services and Public Health Department, Wellness for Every Body (WFEB), which includes an online training program for direct service providers [11]. In 2013, WFEB was recognized as a Promising Practice by the National Association of County and City Health Officials Model and Promising Practices Program. The WFEB uses an environmental approach that targets adult care homes for intervention and creates conditions that establish healthy living as the norm. The training is available 24/7 to teach the basics of nutrition, cooking, and physical activity so direct service providers can support active living and healthy practices in group homes and organizations serving people with I/DD.

## Resources Designed for Children with IDD

A program designed specifically for children is the Healthy Weight Research Network and their Health U curriculum. The Health U curriculum provides nutrition professionals with age-appropriate materials for promoting physical activity and a healthy diet. The Healthy Weight Research Network website provides links to additional resources designed to promote health behaviors for children and adolescents with IDD.

The "OrganWise Guys" uses character representations of different organs to teach children about the impact of health related decisions on one's body. The puppet and stuffed animal characters present information to children in an approachable, familiar medium. The "OrganWise Guys" has extended their curriculum to include children with IDD. The website provides a variety of materials designed for different settings, including parents, schools, after school programs, and summer programs. Age appropriate evaluation kits are provided so change in health awareness can be documented.

## Resources for Individuals with IDD Living in Rural Settings

Individuals with IDD who live in rural settings can also have high levels of obesity and limited access to resources. Factors contributing to rural obesity can include: lack of nutrition information and programming, limited access to obesity prevention and treatment services, challenges related to community infrastructure, such as lack of sidewalks, trails, and exercise facilities. As rural communities have limited resources to address a variety of health-related needs, it is important to begin by identifying the needs of the community through surveys, questionnaires, focus groups,

public meetings, direct observations, and/or interviews in collaboration with families, local businesses, faith-based groups, health department, schools, etc. The Rural Health Hub created a rural obesity prevention toolkit that is designed to help create an obesity prevention program, identify factors in the community that promote obesity, convene partners to help address those problems (e.g., providers and schools), and apply proven obesity prevention strategies. For individuals residing in rural communities, the Rural Obesity Prevention Toolkit may be combined with IDD specific information to develop a program suitable to rural locations.

## National Resources

Community organizations, such as fitness facilities and recreation areas should be inclusive and provide staff training on assisting individuals with IDD. Resources for staff training and promoting inclusion may be obtained from a number of organizations/departments including: the National Center on Health, Physical Activity and Disability; the Special Olympics Healthy Athletes program; and the U.S. Department of Health & Human Service's "I Can Do it You Can Do It" program. Collectively, these resources provide a variety of options for adapting health related materials for individuals with IDD.

These resources, as well as statements from the Surgeon General and other government programs, emphasize the importance of increased availability of health resources and health facilities for people with IDD. Information for public health professionals implementing inclusive programs that are accessible to people with all disabilities is available through the Public Health is for Everyone toolkit. The toolkit compiles online resources that are vetted as appropriate for individuals with disabilities, and the resources are monitored to ensure they remain up to date. Additional weight management resources are available through the Centers for Disease Control and Prevention (CDC) and American Association on Health and Disability.

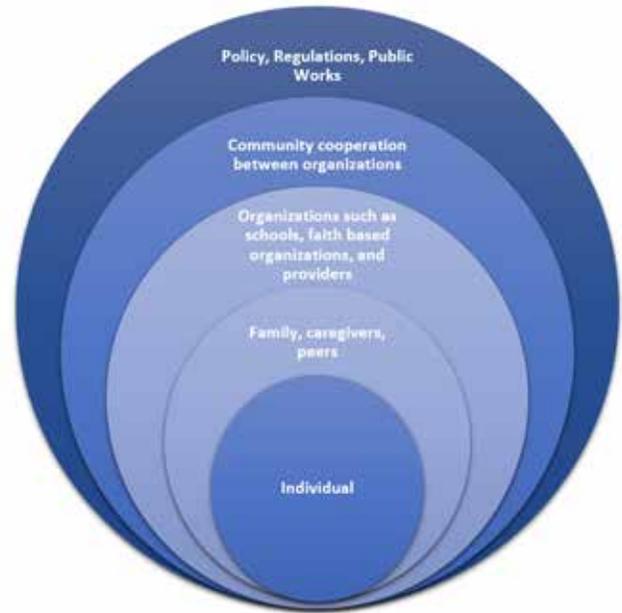
## Policy Recommendations

Regardless of an urban or rural setting, collaboration between providers, the community, family members, and the individual is critical for creating initiatives that are considered multi-level. A large shift in obesity rates among people with IDD will require participation from all these levels. A multi-level approach reflects the CDC's social-ecological model, illustrated in Figure 1.

Successful change in weight management for people with IDD will span across the socio-ecological model from systems and structural change to intrapersonal behavior change. Overall, increased inclusion, support, and access to adapted materials will increase the potential for success in improving weight management for people with IDD. Seeking consultation with a primary health professional is recommended if there are concerns related to weight management behaviors. We provide the following policy recommendations for addressing obesity and individuals with IDD.

1. Adapt behavioral weight management strategies to individuals with IDD. Inclusion of feedback from individuals with IDD and/or caregivers can be highly beneficial in adapting a weight management intervention to the unique needs of people with IDD [12]. For example, there may be limited opportunities for dietary changes due to food aversions, primarily consuming prepared meals, limited cooking skills, or financial restrictions. Family members must be willing to assist with dietary changes or providers must work with the individual to identify opportunities to address dietary habits. An effective strategy may be to target healthier snack foods and smaller portion sizes during main meals.

2. Consider secondary conditions and factors that influence weight gain in individuals with IDD (e.g., medications, comorbidities, lack of access to nutritious foods, lack of access to physical activity venues, etc.). Providers should seek additional resources and training to ensure the individual with IDD's unique health situation is properly considered. Some resources are provided in this document, while others include transportation options, accessible outdoor recreation facilities, and adaptable programs. Medications or other comorbidities may limit weight loss, but implementing health behaviors can still improve an individual's overall well-being.



**Figure 1.** Social-ecological model of weight management for individuals with IDD. Actions to reduce obesity rates observed in people with IDD should extend across each level of the model.

3. Continuing education programs both onsite and online (i.e., webinars) should include effective weight management strategies for adults with IDD that can be readily implemented in various types of settings where adults with IDD live.
4. Increased caregiver and social support has been demonstrated as effective in weight management for individuals with IDD. Regardless of caregiver type, consistent support and attention are key predictors for successful weight loss [13]. Families must be committed not just to changing their young or adult children's habits, but to changing their own – buying, preparing and eating healthy foods as a family and incorporating pleasurable fitness activities into family life. Community activities can support health promotion for the entire family, while also providing the opportunity for the individual and family to engage with others. Decisions made by the family and caregivers must still be respectful of the individual's autonomy.
5. Ensure future policy is inclusive of individuals with IDD. Given the paucity of information regarding weight management for individuals with IDD, this group of people is often overlooked when general healthcare policies are drafted. Policy mandates for inclusion of all peoples can contribute to the overall health of the population, and especially vulnerable populations.

## Conclusions

Individuals with IDD exhibit higher rates of obesity and lower rates of physical activity when compared to the general population. Obesity is a growing health concern that can negatively impact the physical, mental, social-emotional health of an individual with IDD. Individuals with IDD who are obese also have greater risk for other metabolic diseases, such as diabetes and cardiovascular disease. Increased effort is needed for obesity prevention and weight management for people

with IDD. Providers must consider addressing various issues using the social-ecological model as a framework for addressing barriers from policy (i.e., systems) to individual behavior change (i.e., individual). Research reports do indicate multi-component/multi-level interventions that incorporate, physical activity, nutrition, and behavior change have been most effective. Community programs for individuals with IDD should incorporate evidence-based research interventions and promising practices. Addressing weight management for an individual with IDD is a collaborative effort that includes the individual, families, providers, community partners, and public resources.

## Resource Links

- American Association on Health and Disability: [www.aahd.us](http://www.aahd.us)
- CDC: [www.cdc.gov/obesity/](http://www.cdc.gov/obesity/)
- Health Matters: [www.healthmattersprogram.org](http://www.healthmattersprogram.org)
- Healthy Weight Research Network: [www.hwrn.org](http://www.hwrn.org)
- I Can Do It, You Can Do It: [www.hhs.gov/fitness/programs-and-awards/i-can-do-it-you-can-do-it/index.html](http://www.hhs.gov/fitness/programs-and-awards/i-can-do-it-you-can-do-it/index.html)
- NCHPAD: [www.nchpad.org](http://www.nchpad.org)
- Public Health is for Everyone: [www.phetoolkit.org/index.cfm](http://www.phetoolkit.org/index.cfm)
- Rural Obesity Prevention Toolkit: [www.ruralhealthinfo.org/community-health/obesity](http://www.ruralhealthinfo.org/community-health/obesity)
- Special Olympics: [www.specialolympics.org](http://www.specialolympics.org)
- The Arc HealthMeet: [www.thearc.org/healthmeet/about](http://www.thearc.org/healthmeet/about)
- The OrganWise Guys: [www.organwiseguys.com](http://www.organwiseguys.com)
- Wellness for Every Body: [www.hennepin.us/residents/health-medical/public-health-promotion](http://www.hennepin.us/residents/health-medical/public-health-promotion)

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