

OBESITY AND INTELLECTUAL DISABILITY

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While much of the industrialized world struggles for clues to the growing rise in obesity in their respective countries, researchers and service providers involved in understanding the health characteristics and health behaviors of persons with intellectual disability (ID) struggle with their own issues regarding the increased prevalence of obesity in this segment of the population. What is particularly alarming is that adults with ID residing in the United States in smaller, less supervised settings (e.g., group homes and family households) have a significantly higher rate of obesity compared to other countries and those living in larger and more supervised settings (e.g., institutions). These differences support the theory that the environment appears to exert a powerful influence on obesity in this population. Obesity presents a substantial threat to the livelihood of persons with ID and may have an effect on community participation, independent living, and healthy years of life. The lack of research on successful weight reduction strategies for obese persons with ID makes this an important and greatly needed area of research.

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MRDD Research Reviews 2006;12:22–27.

Key Words: obesity; intellectual disability; developmental disability; health promotion; health status

Obesity is a serious health risk among many individuals and groups throughout the industrialized world and often leads to various health conditions including hypertension, diabetes, heart disease, arthritis, stroke, stress, depression, and respiratory diseases [Eckel, 1997; National Institutes of Health, 1998; Must et al., 1999; Pi-Sunyer, 1999; National Task Force on the Prevention and Treatment of Obesity, 2000]. In the United States, obesity has more than doubled from 13.4% in 1960 to 30.9% in 2000 [Flegal et al., 2002]. As a result of this substantial increase, the U.S. Surgeon General declared that obesity has reached epidemic proportions in the nation and called for an immediate action to prevent and reduce its impact on both the individual and society at large [U.S. Department of Health and Human Services, 2001].

Researchers have also recognized that obesity is a major health threat in persons with intellectual disability (ID) [Fox and Rotatori, 1982; Kelly et al., 1986; Rimmer et al., 1993; Rubin et al., 1998; Horwitz et al., 2000; Janicki et al., 2002; Traci et al., 2002]. Population-level prevalence data indicate that the obesity levels of adults with ID are either similar to or higher than their non-ID counterparts [Emerson, 2005; Yamaki, 2005]. Lack of healthy eating habits and regular physical activity, common factors associated with obesity in the general population [U.S. Department of Health and Human Service, 2001], are also growing problems among persons with ID [Draheim et al., 2002; Braunschweig et al., 2004; Emerson, 2005].

Obesity results in significant societal and personal costs [Poston and Foreyt, 1999]. Among persons with ID, it has the

potential to reduce or limit opportunities for various types of community participation, including employment and leisure. It can also require greater effort on the part of the caregiver in assisting the individual with ID with various activities and instrumental activities of daily living. Additionally, higher medical costs associated with obesity-related chronic health conditions may become a greater issue in the ID population as life expectancy increases [Janicki et al., 2002; Fisher and Kettl, 2005]. This article reviews the prevalence data on obesity in adults with ID and discusses environmental factors that may be linked to obesity in this population.

OBESITY PREVALENCE IN AMERICAN ADULTS WITH ID

Several studies conducted in the United States have reported a higher prevalence of obesity among persons with ID compared to non-ID citizens [e.g., Rubin et al., 1998; Harris et al., 2003; Rimmer and Wang, 2005; Yamaki, 2005]. In particular, women, older individuals, and those with less severe disabilities and certain genetic causes of obesity (i.e., Down syndrome) were more likely to be obese compared to their counterparts [Fox and Rotatori, 1982; Kelly et al., 1986; Rimmer et al., 1993; Rubin et al., 1998].

Fox and Rotatori [1982] examined the body weight of over 1,100 individuals with ID who resided in an institution and several community-based residential programs. Overall, 15.6% of men and 25.1% of women were obese (i.e., at least 120% heavier than desirable weight). Individuals with mild/moderate limitation reported a higher rate of obesity than their counterparts with profound/severe limitation. They also found that, in general, obesity was more prevalent in older individuals with ID for both genders.

Kelly et al. [1986] measured percent body fat using skin-fold thicknesses in 553 institutionalized residents with ID and reported that 45.2% of men and 50.5% of women were obese (i.e., percent body fat \geq 20% for males and 30% for females).

This publication is supported by grant #U59/CCU521217 from the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC); and grant #H133B980046 from the National Institute on Disability and Rehabilitation Research, RRTC on Aging and Developmental Disabilities. Its contents are solely the responsibility of the authors (association or center) and do not necessarily represent the official views of the CDC.

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Received 2 November 2005; Accepted 4 November 2005

Published online in Wiley InterScience (www.interscience.wiley.com).

DOI: 10.1002/mrdd.20091

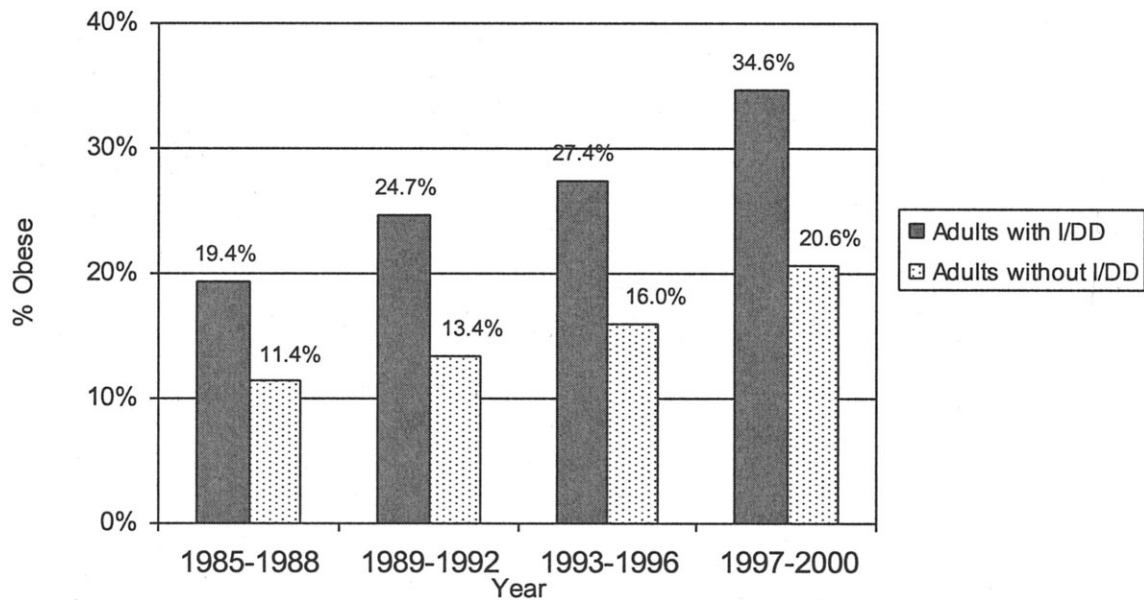


Fig. 1. Prevalence of obesity among U.S. adults by the presence of intellectual disability (ID), 1985–2000.

Rimmer et al. [1993] compared obesity levels (percent body fat $\geq 25\%$ for males and 30% for females) in adults with ID residing in three different settings—family, community-based facilities, and institutions. They reported that the overall rate of obesity was 27.5% for men and 58.8% for women. Lewis et al. [2002] reported that 29.2% of 350 adults with ID living in and around Los Angeles, CA were obese [body mass index (BMI) ≥ 30]. These individuals represented a group of persons with ID who received support services from a large state-operated regional center in the area. Harris et al. [2003] measured the height and weight of 443 adults with ID who participated in the Special Olympics World Games. Of those, 26% were obese (BMI ≥ 30) and an additional 6% were extremely obese (BMI ≥ 40). The researchers reported that the rate was significantly higher for the U.S. participants compared to participants from other countries.

Yamaki [2005] estimated obesity prevalence among adults with ID by analyzing U.S. population-level household survey data. This data set was more likely to include a broader representation of people with ID who were supported by family members in the community but were not necessarily part of the ID service system [Fujiura, 1998; Yamaki and Fujiura, 2002]. Across 16 years of annual survey data from 1985 to 2000, over 1 million Americans participated in this household survey. Of those, 3,499 were identified as persons with ID based on self-reported presence of mental retarda-

tion. Body weight status of the survey participants was determined using self-reported weight and height information. As illustrated in Fig. 1, statistically weighted national level estimates indicated that the prevalence of obesity (BMI ≥ 30) among persons with ID was significantly higher than the general population at each of four 4-year observation periods and has been increasing steadily over this period. Yamaki [2005] concluded that many adults with ID were at risk for developing chronic health conditions secondary to their primary impairment.

Rimmer and Wang [2005] measured the height and weight of 306 adults with disabilities from the Chicago area, which included a subset of adults with ID. As illustrated in Fig. 2, the prevalence of obesity (BMI ≥ 30) and extreme obesity (BMI ≥ 40) was very high in adults with ID (listed in the figure as mental retardation and Down syndrome). Strikingly, the rate of obesity was twice as high compared to the general population, with 70.7% of adults with Down syndrome and 60.6% of adults with mental retardation without Down syndrome classified as obese compared to only 30.5% for the general population [National Center for Health Statistics, 2002]. What was particularly alarming was that extreme obesity was four times higher in adults with Down syndrome (19.0%) and 2.5 times higher in adults with mental retardation without Down syndrome (12.1%) compared to the general population (4.7%). These data must be interpreted cautiously because the sample was

from one city in the Midwest (Chicago) and the participants were not randomly selected. However, the findings appear to support the work of other studies that Americans with ID have a greater prevalence of obesity and extreme obesity compared to the general population.

OBESITY PREVALENCE IN ADULTS WITH ID OUTSIDE THE UNITED STATES

Researchers from other industrialized countries also found a higher prevalence of obesity and gender differences among persons with ID compared to their native population. Based on actual measurements of body weight and height of 183 British men and women with ID living with other family members, Bell and Bhate [1992] found that 19.0% of men and 34.6% of women were obese (i.e., BMI ≥ 30). In a sample of 321 adults with ID who resided in Northern Ireland, Marshall et al. [2003] reported that 32% were obese (BMI ≥ 30), and 4.2% were classified in the extremely obese category (BMI ≥ 40). In a sample of adults with ID ($n = 202$) residing in Sydney, Australia, 16.3% of men and 26.5% of women were obese (i.e., BMI > 30). These rates were much higher than men and women without disability, who had prevalence rates of 7.7% and 8.5% , respectively, residing in the same locality [Beange et al., 1995]. Among 1,300 individuals with ID in Northern England, Emerson [2005] found that 27% were obese (i.e., BMI ≥ 30). The researcher also noted that women generally reported a higher rate

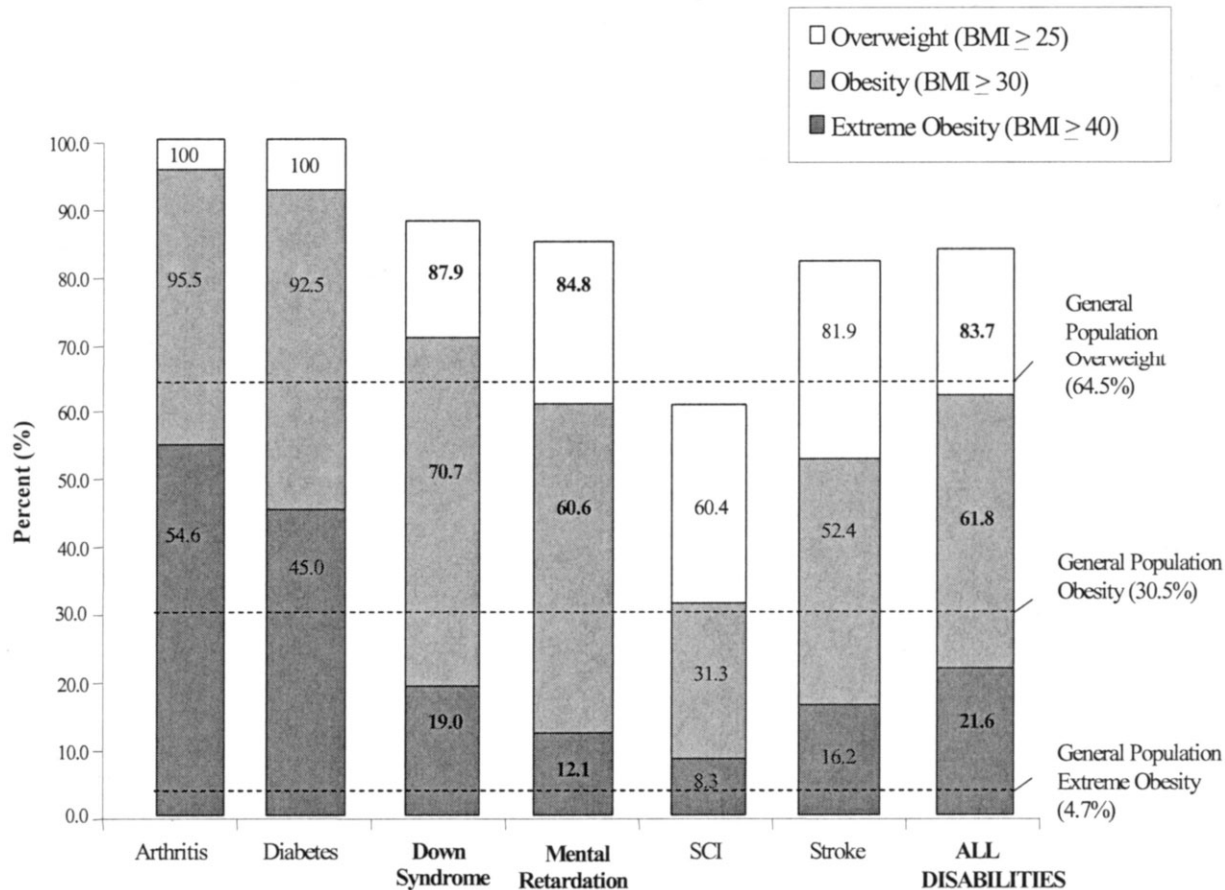


Fig. 2. Overweight, obesity, and extreme obesity prevalence among various disability groups, including mental retardation and Down syndrome.

of obesity than men across age cohorts. Frey and Rimmer [1995] utilized two measurements, percent body fat (skin-folds) and BMI, to determine the obesity prevalence among German adults with ID. Using percent body fat ($\geq 25\%$ for males and 30% for females), researchers found that 16.7% of persons with ID living either in an institution or with families in southwestern Germany were obese and that females were more likely to be obese than males. Table 1 summarizes the prevalence of obesity (i.e., $BMI \geq 30$) in persons with ID across different countries.

A POSSIBLE LINK BETWEEN OBESITY AND THE ENVIRONMENT IN PERSONS WITH ID

The genetics versus environment theory of obesity has been a topic of much debate for the past 30 years. Basic scientists purport that genetic factors play a more important role, while epidemiologists argue that obesity is a product of the environment [Poston and Foreyt, 1999]. Proponents of the environment theory argue that the greater availability

of food and lack of incentive to be physically active have led to a higher rate of obesity in the United States. [Binkley et al., 2000; Handy et al., 2002; Swinburn and Egger, 2002; Bowman and Vinyard, 2004].

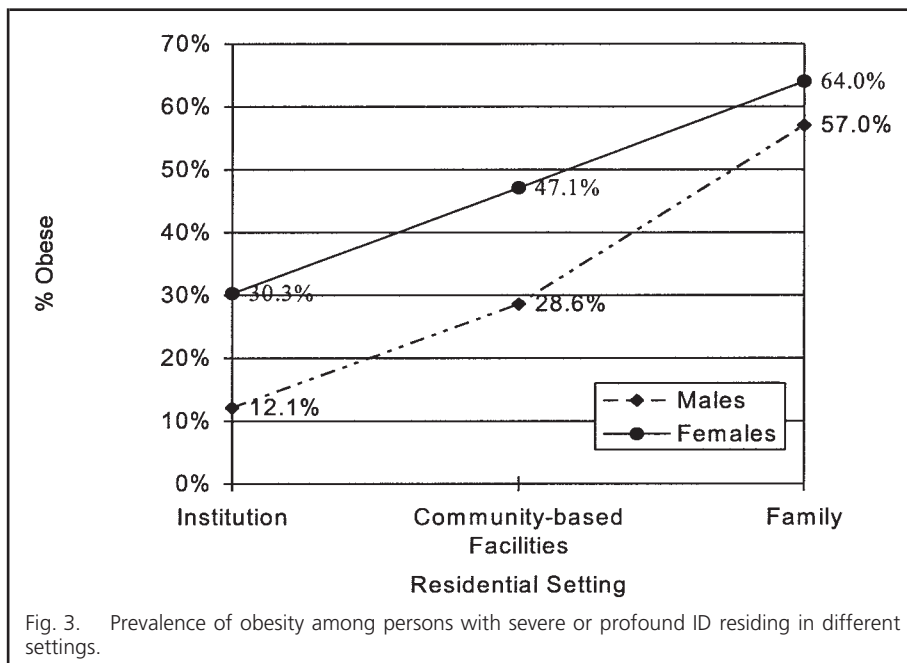
Among persons with ID, a similar theory is emerging. When comparing obesity prevalence in persons with ID residing in different living arrangements, researchers consistently found that those who lived in less restrictive settings were more likely to be obese than those who lived in more supervised settings [Rimmer et al., 1993, 1994; Frey and Rimmer, 1995; Prasher, 1995; Rubin et al., 1998; Lewis et al., 2002]. For example, as illustrated in Fig. 3, Rimmer et al. [1993] found that individuals with ID (same level of severity) who lived with their families reported the highest rate of obesity, followed by those who lived in the community-based residential facilities. Obesity was least prevalent among individuals who resided in the institutional setting. This work was supported by Lewis et al. [2002] who also reported that obesity was more common among individuals who were living independently

or with family/friends than those who resided in community-based residential facilities.

A similar difference in obesity prevalence across different living arrangements was reported for German individuals with ID [Frey and Rimmer, 1995]. As shown in Fig. 4, German adults residing in an institutional setting had significantly lower obesity levels compared to their counterparts in family settings. None of the German males residing in the institutional setting were obese, and the highest level of obesity was recorded in American females (80%) residing in the family setting. In both settings, the Americans were significantly more obese than the Germans. Unfortunately, the study was strictly descriptive in nature and the researchers were only able to speculate that differences in lifestyle behaviors (e.g., German adults with ID seemed to rely more on walking and bicycling as their means of transportation to and from work, etc.) may have contributed to these differences. It also should be noted that level of ID was not controlled for in this study, and it is pos-

Table 1. Prevalence of Obesity (BMI \geq 30) among Adults with ID across Industrialized Countries

Country	Study	Sample	Obesity (%)	Note
United States	Lewis et al. (2002)	Representative group from Los Angeles, CA ($n = 350$)	29.2	
	Harris et al. (2003)	Adult participants of Special Olympics World Games ($n = 443$)	32	Includes 6% with extreme obesity (BMI \geq 40)
	Rimmer and Wang (2005)	Adults living in Chicago, IL ($n = 149$)	60.6 without Down syndrome 70.7 with Down syndrome	Extreme obesity: 12.1% without Down syndrome; 19.0% with Down syndrome
	Yamaki (2005)	Representative subjects of noninstitutionalized Americans ($n = 3,499$ for 16 years)	19.3 for 1985–1988 23.7 for 1989–1992 27.4 for 1993–1996 34.6 for 1997–2000	Secondary analysis of 16 years of national-level household survey data
England	Bell and Bhate (1992)	Adults living with other family members across England ($n = 182$)	19.0 for men 34.6 for women	
	Emerson (2005)	Residential service users in Northern England ($n = 1304$)	27	
Ireland	Marshall et al. (2003)	Adults living in Northern Ireland ($n = 321$)	36	Includes 4.2% with extreme obesity (BMI \geq 40)
Australia	Beange et al. (1995)	Representative sample from Sydney ($n = 202$)	16.3 for men 26.5 for women	
Germany	Frey and Rimmer (1995)	Southwestern Germany ($n = 105$)	6.8 for individuals in institution 23.9 for individuals living with family	



ical activity [Rimmer et al., 1995; Daley, 1996]. While the level of restriction and supervision constitute an interesting perspective for conducting future research on environmental characteristics that have an effect on higher or lower levels of body weight/obesity among adults with ID, other factors may also be contributing to these differences. Despite the fact that limited cognitive ability of persons with ID is likely to hinder their ability to foresee health consequences of obesity in the future [Edgerton et al., 1994; Spitalnik and White-Scott, 2001], individuals with ID may have limited opportunities to obtain knowledge and to learn health promotion strategies as part of community living skills training [Jobling, 2001]. Providing individuals with ID living choices that foster greater freedom and independence in the community is one of the most important and compelling issues for ID service providers and may overshadow the need for health promotion efforts that identify successful strategies for maintaining body weight through good nutrition and increased participation in physical activity.

Low-income status reported in the majority of the population with ID [Fujiura and Yamaki, 1997; Yamaki and Fu-

sible that a disproportionate number of subjects with severe ID resided in the institutional setting.

Provision of the least restrictive environment and respect for individual choice have been the philosophy of the

intellectual disability services community in the United States and other nations for the past three decades. It is unclear if this freedom of choice has indirectly and unintentionally resulted in poorer food selection and a lowered emphasis on phys-

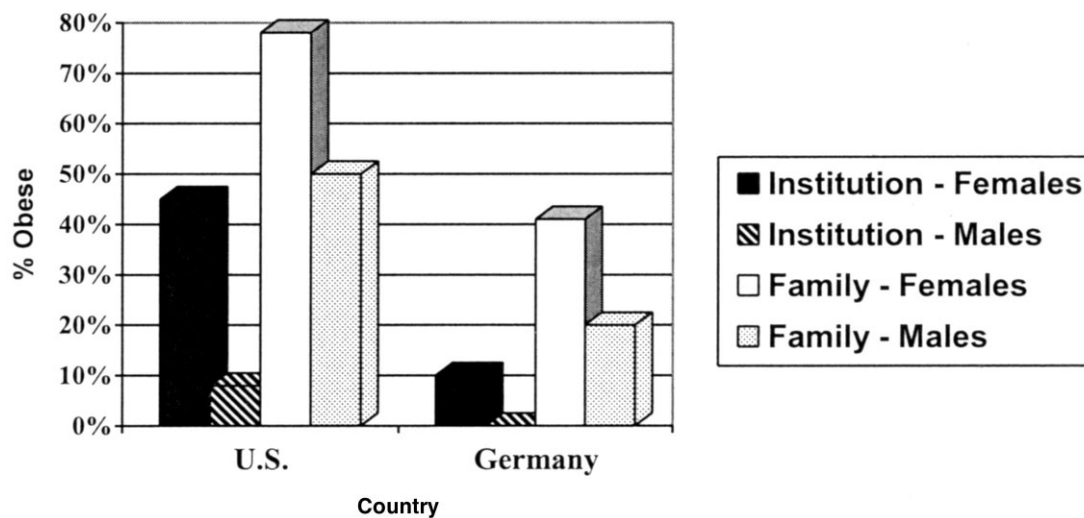


Fig. 4. Frequency of obesity among American and German individuals with ID by sex and living arrangement.

jiura, 2002] may limit access to healthy food choices and exercise venues such as fitness centers (i.e., cost of membership and transportation to get to the facility) [Heller et al., 2002]. Fujiura et al. [1997] suggested that friendships and opportunities for social activities could have a stronger effect on body weight status of persons with Down syndrome than diet and physical activity. Their findings inferred that a person's living environment (e.g., presence of a friend who one can socialize with; access to leisure and recreation programs in the community) might be as critical as diet and physical activity in addressing obesity among persons with ID. An understanding of other environmental factors that affect physical activity participation and caloric intake (e.g., safe communities, sidewalks, variety of walking and bike paths, attitudes of families/support staff in providing access to healthy foods and activities, availability of grocery stores that sell fresh fruits and vegetables) is important to determine reasons for the disproportionately higher prevalence of obesity among people with ID.

Results of these studies suggest that several environmental factors may have a substantial and powerful effect on the obesity levels of persons with ID who reside in the community. Given that approximately two-thirds of the residential placements for persons with ID in the United States are in small, less restricted community households [Rizzolo et al., 2004] and that many individuals with ID who reside in the community do not receive formal disability services [Fujiura, 1998; Olney and Kennedy, 2001; Yamaki and Fujiura, 2002], it is plausible that the rate of obesity will continue to

increase in this population. The relationship between the environment and obesity levels among people with ID is a critical area of research that needs greater attention from policymakers, providers of ID services, persons with ID, and their family members.

CONCLUSION

Obesity is as much of a health problem among persons with ID as it is in the general population and in certain subgroups, such as women and individuals with Down syndrome, it is a substantially greater problem. Obesity is also more prevalent in the United States compared to other industrialized countries, although obesity prevalence within each country is higher for adults with ID compared to non-ID citizens. The finding that the rate of extreme obesity (BMI ≥ 40) among a small cohort of American adults with ID was disproportionately higher than the general population [Rimmer and Wang, 2005] should be a major concern to the field since extreme obesity is strongly associated with higher rates of morbidity and mortality [Fontaine et al., 2003; Owens, 2003].

Although lifestyle risk factors for disease are well established, fundamental questions remain concerning how the environment impacts the health and function of adults with ID. Current approaches to creating healthier communities for people with ID require greater involvement on the part of direct care staff and family members to facilitate increased access to "healthy" lifestyles, including more opportunities for regular physical activity and greater access to nutritious and affordable food choices. The

environment is far more complex for people with ID who may have limited mobility or must be supervised when traveling in the community. Messent et al. [1999] noted that environmental barriers to physical activity reported by individuals with ID and/or their caregivers include financial constraints (i.e., transportation), limited geographical access, and limited choices and options for community physical activity. A truly facilitating environment is one in which health promotion activities (i.e., physical activity and nutrition) are as accessible for people with ID as they are for people without ID.

Research on factors associated with obesity in persons with ID is needed to determine the relationship between obesity and the environment and to identify potential changes that can positively impact health. While there is growing support for the potential value of altering the environment in reducing obesity prevalence in the general population, there is a general lack of information on how this should be accomplished in persons with ID who live in various types of community settings and who may or may not have control of their own food selection or the amount of physical activity that they can obtain on a regular basis.

Efforts to reduce obesity among adults with ID should be given one of the highest research and service priorities because of its strong association with various health complications (e.g., hypertension, heart disease, type 2 diabetes, arthritis), reduced quality of life, and higher rates of mortality. Within the spirit of the disability movement, *self-determination* and *individual choice* must be the central feature of any effort to en-

courage adults with ID to manage their weight [Heller et al., 2001]. Living a longer and healthier life in the community is a universal agenda for all individuals, including people with disabilities. ■

ACKNOWLEDGMENT

A special thanks to Ms. Blythe Hiss for her assistance in preparing this paper.

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