

Overcoming Weight Problems in Adults With Down Syndrome

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Adults with Down syndrome often need help to keep their weights at healthy levels, and yet the prevention and treatment of overweight among them are rarely addressed. This article provides a brief review of the problem and recommendations to overcome the many barriers to maintaining healthy weight and eating patterns encountered by persons with Down syndrome and their families. The primary causes of their weight problems are environmental; degree of intellectual disability and congenital conditions play lesser roles. Nutr Today. 2014;49(3):109–119

own syndrome (DS) was first identified in 1866 by the English physician John Langdon Down.^{1,2} It is characterized by an extra chromosome on chromosome 21. The incidence of DS is approximately 1 in 733 live births, making it the most common genetic condition in persons with special needs.² Until recently, most persons with DS died in early adulthood of congenital heart defects, pneumonia, or other types of respiratory infections.^{3,4} Better treatments of these comorbidities have lengthened the lifespan of people with DS from the age of 25 years in the 1980s to over 50 years today.^{2,5}

Down syndrome is characterized by low muscle tone, short stature, upward slanting eyes, a flattened nose, small ears, and a single crease across the palm of the hand.^{2,6} Health problems associated with the disorder include poor dentition, celiac disease, and constipation.^{2,6} All of these influence weight and nutritional status; therefore, it is necessary

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to deal with diet-related chronic disease risks associated with overweight that affect the many adults with DS.^{2,5} Today, most adults with DS live in their communities in various supported living situations where they often work part time, volunteer, and learn community living skills. Therefore, the community food- and nutrition-related issues that affect people with DS, as well as their special needs for living healthy lives, must be addressed not only by their families or caretakers but also by those in the wider community.

This article addresses overweight and obesity, which are major health issues among adults with DS. It summarizes the barriers to prevention or treatment and recommends ways to overcome them and to achieve healthy weights and better nutrition.

OBESITY IN ADULTS WITH DS

Prevalence of Obesity

People with intellectual disabilities (IDs) have more complex health issues and higher mortality rates than do those in the general population, and some of these differences are caused by weight problems.⁷ The prevalence of obesity (ie, a body mass index [BMI] >30 kg/m²) in adults with ID is estimated to be about 39% in women and 28% in men older than 16 years, whereas in the general population, its prevalence is 25% in women and 23% in men of the same age.^{8,9} The prevalence of overweight and obesity in the DS population is higher than in other populations with ID and the general population (Table 1).^{8–17} Statistics on the prevalence of overweight or obesity in DS are not definitive. Unfortunately, data stratified by level of ID, setting, and age is not available.

Risk Factors for Overweight/Obesity in DS

The biological risk factors for overweight include hypothyroidism and decreased resting metabolic rate (Table 2).^{18–21} Fujiura et al¹³ found that although the energy intakes in adults with DS were comparable with or below those in the general population, those with DS were still heavier than the US averages.

Although other causes of excess weight are important and need to be dealt with or ruled out, most of the causes of obesity in DS are largely lifestyle and environmentally

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TABLE 1 Reported Prevalence of	Prevalence of Ov		erweight and Obesity in Down Syndrome (DS) ^{9–17}	Syndrome (DS)	9–17	
	No of Subjects	Overweight (DS Only	t (DS Only)	Obese (DS	S Only)	
Sample	With DS	Men	Women	Men	Women	Authors
Adults (aged 20–68 y) with ID in day centers (n = 183)	58	38% (BMI ≥25 kg/m²)	57% (BMI ≥25 kg/m²)	32% (BMI≥30 kg/m²)	42% (BMI ≥30 kg/m²)	Bell and Bhate ¹⁰
Adults (aged 20–50 y) with ID (residential setting unknown) (n = 142)	25	NA	4	33% (BMI ≥30 kg/m²)	31% (BMI≥30 kg/m²)	Stewart et al ¹¹
Adults (aged 16–76 y) with DS (residential setting unknown) (n = 201)	201	31% (BMI ≥25 kg/m²)	22% (BMI ≥25 kg/m²)	48% (BMI ≥30 kg/m²)	47% (BMI ≥30 kg/m²)	Prasher ¹²
Adults (aged 16–59 y) with DS living at home or in residential facilities (n = 49)	49 (28 men, 21 women)	32% (>15% ideal weight)	67% (>15% ideal weight)	25% (>125% ideal weight)	43% (>130% ideal weight)	Fujiura et al ¹³
Adolescents and adults (aged 15–69 y) attending a DS clinic (n = 283)	283	45% (BMI≥25 kg/m²)	56% (BMI≥25 kg/m²)	NA	4	Rubin et al ¹⁴
Adults living in Chicago, Illinois (residential setting unknown) (n = 306)	58	88% (BMI ≥25 kg/m²)	≥25 kg/m²)	71% (BMI ≥30 kg/m²)	230 kg/m²)	Rimmer and Wang ¹⁵
Adults (aged ≥16 y) with ID living in various settings (n = 945)	609 (89 men, 92 women)	19% (25 ≥ BMI < 30 kg/m ²)	21% (25 <u>></u> BMI < 30 kg/m ²)	25% (BMI ≥30 kg/m²)	27% (BMI ≥30 kg/m²)	Melville et al ⁹
Adolescents (aged 12–18 y) with IDD (assumed under family care) (n = 461)	81	55% (>85th percentile)	i percentile)	31% (>95th percentile)	percentile)	Rimmer et al ¹⁶
Adolescents and young adults (aged 13–21 y) with DS (assumed under family care) (n = 32)	32 (20 boys, 12 girls)	35% (85th–94th percentile)	33% (85th–94th percentile)	25% (>95th percentile)	8% (≥95th percentile)	Bandini et al ¹⁷
Abbreviations: BMI, body mass index; ID, intellectual disability; IDD, intellectual/developmental disabilities; NA, not applicable.	ss index; ID, intellectual dis	ability; IDD, intellectual/dev	velopmental disabilities; N∠	, not applicable.		

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ABLE 2 Biological and Lifestyle-Related Risk Factors for Obesity in Down Syndrome (DS) ^{6,15,18–26}						
Biological Risk Factors	Lifestyle-Related Risk Factors					
Hypothyroidism	Dietary intake					
Estimated prevalence: 8%–12% (incidence increases with age)	Varies based on residence of individual based on level of supervision and opportunities to make food choices					
Underproduction of thyroid hormones cause energy imbalance, which may contribute to weight gain	BMI is associated with setting					
May cause tired and sluggish feeling and make physical activity difficult	Most individuals consume high-fat diets and do not eat the recommended amounts of fruits and vegetables per day					
Treated with thyroxine replacement						
Lower RMR	Physical activity					
Prevalence and incidence are inconclusive	Physical activity guidelines for Americans with disabilities					
Short stature is positively associated with lower fat-free mass, thereby necessitating fewer energy needs	150 min/wk of moderate-intensity or 75 min/wk of vigorous-intensity aerobic activity					
On an eating pattern containing the same amount of food energy, individuals with DS may be in positive energy balance and storing fat	Adults with DS tend to leave sedentary lifestyles and rarely engage in physical activity or other leisure activities					
Abbreviations: BMI, body mass index; RMR, resting metabolic rate.						

related. Thus, emphasis in treatment should be placed on altering dietary intake and physical activity to achieve and maintain a healthy weight (Table 2).^{5,22,27} In a study of individuals with ID living in community settings, more than 70% of men and women consumed high-fat diets (>30% of calories from dietary fat) and less than 10% of either sex consumed the recommended amount of fruits and vegetables per day.²²

Lack of physical activity is another major contributor to overweight and obesity. In only 1 study did most (60%) adults with DS who were surveyed report that they "exercised" daily, but other studies reported that those with DS were more sedentary than those without DS.²⁸ More than 50% of individuals with ID engage in little or no leisure-time physical activity, just as is true in the general population.²⁴

Consequences of Obesity in DS

The leading causes of death in the United States in 2010 were heart disease, stroke, diabetes, and cancer, all of which are adversely influenced by overweight and excessive dietary intake.^{25,29,30} Weight status and diet also contribute to the development of hypertension, which is a strong risk factor for cardiovascular disease, especially in people with ID.²⁹ Obesity can also cause obstructive sleep apnea, which, if left untreated, can lead to hypertension, heart failure, and death.⁶ Because people with DS have a longer lifespan than in prior times, lead sed-

entary lifestyles, and remain obese, the incidence of these diseases is likely to increase among them in the future.²⁹

BARRIERS TO HEALTHY WEIGHT MAINTENANCE AND NUTRITION EDUCATION

There are no commonly agreed upon, evidence-based weight maintenance and nutrition education interventions for people with DS. Ideally, any weight management and education program should consider the participants' physical and intellectual abilities, which may act as barriers to healthy eating if these are not addressed (Table 3).

Degree of ID

Obesity is inversely correlated with the degree of ID in DS, perhaps because of differences in functionality and degree of independence (Table 4).^{27,31} Adults with DS who have mild to moderate ID generally have higher functional ability compared with those with severe ID, and they tend not to be as closely monitored with respect to their eating and physical activity patterns. Those with severe ID tend to be more dependent on family or caregivers, and their weight status will therefore depend on the actions of their caregivers.

Activities of Daily Living and Instrumental Activities of Daily Living

The DS individual's activities of daily living (ADLs) need to be assessed, including eating, feeding, oral care, and mobility.³⁵ It is also important to evaluate functioning with

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TABLE 3 Barriers to Health (DS) ^{15,16,26,31–33}	BLE 3 Barriers to Healthy Weight Maintenance and Nutrition Education in Down Syndrom (DS) ^{15,16,26,31–33}					
Degree of ID	Obesity is inversely related to the degree of ID because of functional ability and its relationship to living environment.					
	The actual degree of ID may not contribute to overweight and obesity in adults with DS as heavily as the degree of independence and functionality of these individuals in these various settings.					
ADL and IADL	ADL and IADL are associated with functional ability but do not suggest greater knowledge of health and nutrition.					
	ADL and IADL affect what an individual with DS can eat, how it is eaten, what foods are available and accessible, and how much energy is expended on a day-to-day basis.					
Residential setting	Residential setting of the DS individual is determined by the level of ID and functional ability of the individual with DS.					
	BMI is associated with residential setting and tends to be lower in more restrictive settings.					
Knowledge and education	Lower cognitive abilities correlate with less nutrition knowledge and the inability to foresee health risks associated with excessive body weight, thus leading to poor dietary choices.					
	Individuals with DS are often not given the opportunity to gain adequate knowledge in health and nutrition tailored to their intellectual abilities and skills.					
Socioeconomic status	Greater opportunities to choose high-calorie and high-fat foods in low-income settings.					
	Low income status is associated with suboptimal nutrient intake and low fresh fruit and vegetable availability.					
	More corner stores and fast-food restaurants in low-income areas and lower concentrations of supermarkets.					
	Unsafe or unaffordable means of exercise.					
Access to gyms and activities	Lack of access to gyms and activities because of cost, transportation, and appropriateness of activities at the gym.					
Abbreviations: ADL, activities of daily li	ving; BMI, body mass index; IADL, instrumental activities of daily living; ID, intellectual disability.					

respect to the instrumental ADLs. These are not necessary for basic existence but allow people with DS to live more independently. They include food preparation, shopping, transportation, and managing finances.³⁵ Adults with DS who are more independent usually have higher ADLs and instrumental ADLs. However, they may not have the knowledge to choose and prepare healthy foods independently, and so they too need help.

Residential Settings

Rimmer et al¹⁵ found that adults with ID who live in less restrictive settings are more likely to be obese than those who live in more supervised environments. Obesity is less prevalent in residential settings, where there is more control by staff over meals and activities.²⁶ Why this is so may be because people with mild to moderate ID often make their own, sometimes unhealthy, choices regarding food and exercise.^{15,22,24,26,32} It is also possible that family members use food as a reward or as a bribe to induce compliant behavior, which creates adverse incentives for healthy eating and inappropriate food choices.

Knowledge and Educational Barriers

The level of knowledge of the individual with DS and that of his/her caretakers varies. A study conducted on 38 Australian teenagers with DS and their families found that only 53% of the teenagers understood the benefits of exercise, and their knowledge about healthy eating was also poor.²⁸ When asked about favorite foods, 58% of the teens with DS chose foods high in fat and sugar, and 81% reported eating them daily.²⁸ Although 72% of the participants reported understanding the relationship between health and diet, only 2 of the 38 teenagers could describe what the relationship might be.²⁸ Less than half could accurately name a healthy food when asked, and 31% named foods high in fat, whereas 25% did not know.²⁸ Moreover, 37% of participants considered soft drinks to be healthy, whereas only 21% believed milk was healthy.²⁸

TABLE 4	Levels of I	ntellectual Disabilities and Characteristics at Each Level ³⁴
Level	IQ Range	Characteristics/Abilities
Mild	50–70	Participates in and contributes to their families and communities
		Works in supported or open employment
		May live and travel independently with some support and help with finances and events in daily life
		Capable of learning to read and write
		May develop important relationships, marry, and have a family with outside support
Moderate	35–50	Participates in a range of activities with family, friends, and acquaintances
		Understands schedules and events if provided with pictures and visual prompts
		Makes choices and has preferences about when he/she would like to do, eat, drink, etc
		May recognize some words in context that are used commonly
		May develop independence in personal care
		May have important relationships
		Requires lifelong support in planning and organizing tasks and activities
Severe	<35	Recognizes familiar people and may develop strong relationships with family or caregivers
		Little or no speech; relies on gestures, facial expressions, and body language to communicate
		Requires lifelong assistance with activities of daily life, communication, and accessing/participating in services and activities
Abbreviatio	n: IQ, intelligence	quotient.

Given the lack of knowledge or understanding about health and food, it is not surprising that 48% of participants chose high-fat or high-sugar meals.²⁸

Socioeconomic Status Barriers

Socioeconomic status (SES) influences obesity risk in adults with DS as it does in other parts of the population. Food choices are based on factors other than nutritional quality, such as cost and preference, and they may become barriers against reducing the prevalence of overweight and obesity.³³ Adults of low SES with DS may be eligible for food assistance programs. It is unknown how many people with DS use these resources, but perhaps, if they were made simpler and easier to understand with assistance provided to gain access to them, there might be an increase in participants with DS.³³

Lack of Access to Gymnasiums and Other Physical Activities

Many adults with DS do not participate in regular physical activity, which may sometimes be because of a poor level of functional ability, but probably more often to barriers due to SES or less access to gyms and recreational activities.^{36,37} Adults with DS may be dependent on other people and means of transportation; therefore, support for transportation is needed to help increase physical activity in this population. In addition, once adults with DS are at a gym or health club, they also need to be provided with equipment and activities that are safe and easy to learn and handle independently. Recreational sports that are more individually based, such as swimming and running, may be easier for adults with DS to partake in because these sports do not incorporate the intellectual complexities of team sports. Special Olympics programs exist in every state and provide a wide variety of individual and team sports in which all persons with ID can participate and increase their physical activity with peers.

Comorbidities

Comorbidities, or secondary conditions that reduce the person's independence, occur frequently in people with DS and make nutrition education more challenging (Table 5).^{6,38} Low muscle tone, a characteristic that is evident in all people with DS, is a major barrier in overcoming overweight and obesity.^{2,6} Hypotonia, as well as other physical limitations like hypermobility, may make physical activity more difficult

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TABLE 5 Comorbidities That Are Barriers in Down Syndrome ^{6,31,38–40}								
Comorbidity	Characteristics	lssues	Recommendations to Overcome Barriers					
Hearing and vision	Various degrees of hearing and vision loss	Affects how health information is presented to people with Down syndrome	If hearing loss is the primary issue, concepts taught will need to be visual that incorporates pictures for easy understanding					
		Impedes ability to independently shop for healthy foods	If vision loss is the main barrier, concepts will need to be taught verbally and require more repetition					
			Both hearing and vision loss may necessitate sole education to caregivers					
Mental health and cognition	Mental health deteriorates with age	Communication, fatigue, and decreased memory may inhibit the ability to learn and apply healthy eating to lifestyles ³⁸	Medication may be necessary to treat anxiety and depression and to slow the progression of Alzheimer's disease					
	Anxiety, depression, social withdrawal, loss of interest, diminished self-care, dementia, and Alzheimer's disease are common	May also lead to a decline in routine activities and abilities	Repetition with multiple examples may increase memory/learning capacity					
Behavioral problems	Attention deficit disorder, impulsiveness, inattentiveness, obsessive-compulsive behavior, oppositional behaviors	May not directly affect weight but impairs caregivers' abilities to communicate nutrition education effectively	Treat the underlying cause of the behavioral problem with medication and/or behavioral therapy					
	May be caused by underlying medical problems: hearing, vision, gastrointestinal, thyroid, anemia, constipation, depression, anxiety, and sleep							

and may prevent individuals from engaging in exercise and doing it effectively. Thus, increasing muscle mass, and thereby increasing metabolism, may be more difficult to achieve.³⁷

Some people with DS may also have sensory processing disorders (SPDs) in vision, hearing, or touch that affect their dietary intake.⁴¹ Adults with DS who have SPD may avoid certain foods that stimulate a negative response due to the sights, smells, sounds, tastes, and textures of the particular food. Therefore, SPD can make nutrition education difficult because dietary choices and exercise in these individuals are not necessarily knowledge based. In these situations, therapeutic interventions may be more beneficial than simple educational measures at integrating healthy foods into these individuals' diets.

RECOMMENDATIONS FOR INTERVENTIONS WITH DS

The prevention and treatment of obesity in DS are best approached from a multidisciplinary perspective. Actions are needed at all levels of care throughout the life stages (Table 6).

What Registered Dietitians and Nutritionists Can Do to Prevent Overweight/Obesity in DS

Dietitians can be helpful at all life stages of individuals with DS with different levels of ID. Monitoring and assessing weight and nutritional status are important at all ages. Currently, standard practice is to plot a child on both DS and Centers for Disease Control and Prevention growth charts and to make an educated assessment from the interpretation of both charts. According to the American Academy of Pediatrics, however, clinicians should use the standard growth charts when assessing patterns of growth and weight gain, which should include weight for height and BMI.⁴² Down syndrome growth charts are not reflective of the current population, and clinicians should use the Centers for Disease Control and Prevention growth charts until new DS growth charts are developed.⁴² For adults with DS who are older than 20 years, BMI is the only tool

			Level of ID		Setting			Age			
			Mild	Moderate	Severe	Independent living	Family	Assisted living	Childhood	Adolescence & pre- adulthood	Adulthood
		Monitor weight and nutritional status and determine energy needs									
		Develop menus and meal plans for individual									
4)		One-on-one counseling									
the		Group counseling									
n vith		Provide resources for food assistance									
lg v atio	ons	Assess dietary concerns and feeding skills									
-kin Duls	Actions	Work with caregivers to develop meal plans Educate caregivers									
Dietitians working with the DS population	7	Monitor growth on DS growth charts (Note: there are no growth charts for adults with DS) Prepare individuals with knowledge and skills to make healthy choices									
Di		Reinforce knowledge and skills with hands-on teaching (ex. Cooking together)									
q	_	Food groups									
an	dua	MyPlate									
ials	livi	Diet and health									
ion for individus groups with DS	topics for indiv group sessions	Energy balance									
ith ith	i foi ses:	Food shopping									
r ir s v	pics Jup	Meal preparation									
n fo	toj gre	Portion control									
gr gr	ution and	Ordering from a menu Label reading									
Education for individuals and groups with DS	Education topics for individual and group sessions	Healthy eating on a budget									
		Food safety									
		Resources; e.g. food assistance and food banks Motivation to change									
		Challenges and experiences of individuals									
		One-on-one counseling									
		Group counseling									
	Teaching considerations	Teach concepts with stories, toys, games, crafts, etc.									
	Teaching nsideratior	Teach concepts through participatory activities; e.g. cooking									
	lea(demos									
		Teach with multiple pictures and models									
		Use simplified terms and concepts Establish individual exercise programs and meal plans									
		Identify foods high in calories, fat, and sugar			-						
		Understand the relationship between health and diet			-						
	Expected outcomes	Identify the relationship between health and diet									
		Understand the concept of energy balance									
		Understand health risks associated with excess body weight									
		Construct balanced meals and snacks									
	uc	Healthy eating and meal preparation									
DS	Education	Dietary and physical activity guidelines									
ith I		Health benefits of physical activity and diet				<u> </u>					
le w	Щ	Barriers to healthy eating				ļ					
lqos		Involve individuals with DS in meal planning & preparation									
f pe	Ħ	Prepare meals that meet dietary needs									
Caregivers of people with DS	vemer	Provide supervision & recommendations during meal preparation									
egiv	Involvement	Engage individuals with DS in daily physical activity									
Car		Avoid using food as a bribe				ļ					
-		Educate on health issues, consequences of poor food choices, and healthy alternatives									

TABLE 6 Recommendations for Interventions in Individuals With Down Syndrome (DS)

that is available. Dietitians should recognize, however, that the BMI of adults with DS may need to be interpreted differently because DS patients often show signs of premature aging, including diabetes, hypertension, and functional decline, that are influenced by overweight and obesity.⁴³ Nutritional assessment for people with DS should include anthropometry, biochemistry, clinical assessment, and dietary intake, with an emphasis on physical activity, feeding ability, oral health, fluid and fiber intake, nutrition knowledge, and access to healthy foods.

Dietitians must also help adults with mild to moderate ID associated with DS who live more or less independently. Some people with DS have inappropriate eating behaviors similar to those of the general public, including consumption of high-fat foods and low levels of physical activity.^{22,24,26} Diets high in fat may lack protein and the vitamins and minerals, such as vitamins A, C, and E and zinc, that support immune health and reduce oxidative stress.⁴⁴ Thus, diets poor in nutritional quality, often associated with obesity, may be more detrimental in individuals with DS who may have an inherently compromised immune system.^{44,45} To promote overall health and healthy weight, dietitians should emphasize balanced diets high in fruits and vegetables to incorporate these essential nutrients. Dietitians can help adults with DS and their caretakers by providing them with the skills necessary to make healthier food choices.

All healthcare professionals who intend to work with the DS population should seek opportunities that expose them to everyday issues related to DS. *The Down Syndrome Nutrition Handbook* by Joan Medlen, MEd, RD, LD, is a useful resource for healthcare professionals working with people with DS.⁴⁶

Education

Early intervention in children with DS has been shown to have long-term positive effects on cognition, communication, and social-emotional functioning, and therefore, it should be encouraged.^{47,48} All 3 components may have a positive impact on the individual's ability to learn about health and nutrition later on as an adult. Health and nutrition education in childhood may show long-term effects on nutritional and weight status as adults.

Children with DS need health and nutrition information to prepare them for the transition from family care to independent living or community living when they reach adulthood. Adults with DS and their families should be aware of and seek out services that may be offered through the state in which they live. These individual support plans should include programs or individual supports for teaching persons about healthy eating, cooking skills, grocery shopping, and exercising. It is important that the health information provided be easy to comprehend, and educational materials and techniques should be tailored to their learning abilities, living situation, finances, preferences, health, and physical abilities.

Health Promotion Programs

Adults with DS may benefit from health promotion programs either through the community or through the residences in which they live. People with DS often have reduced short-term memory and a short attention span, and so adults with DS may learn better with short, succinct lessons repeated many times.⁴⁹ Health promotion programs need to address the issue of poor dietary intake that follows a model that integrates behavioral, environmental, and medical factors in an effort to increase knowledge, preferences, skills, and self-efficacy.⁴⁹

Some weight loss interventions have shown a reduction in mean BMI over a period as little as 6 weeks (the level of ID and setting were not provided for the participants in this study, however).^{50,51} Mann et al³¹ found that fruit and vegetable consumption increased with increased knowledge among people with ID. One study on the effects of physical activity on weight loss in participants with DS found no changes in weight but found improvements in cardiovascular fitness, muscle strength, and endurance.⁵⁰ Thus, although physical activity–based interventions are not effective in weight loss, they may be beneficial in preventing weight gain and the development of other diseases.⁵⁰

Education and Involvement of Caregivers

Educating caregivers is a necessary step in preventing and treating obesity in DS because some caregivers have negative influences on dietary intake and physical activity.^{52–54} Melville et al⁵⁴ found that caregivers generally have poor knowledge of physical activity recommendations (frequency, duration, and intensity) and poor dietary knowledge, particularly about recommendations for daily intake of total fat, calories, and sodium. Caregivers heavily weighted knowledge and skills, motivation for change, and lifestyle choices as the main barriers for the people whom they cared for. Finances, transportation, and lack of personal choice were less heavily weighted.⁵⁴ In fact, these latter factors are truly significant barriers to healthy lifestyles for people with ID, and helpers of all types should be made aware of them.

Caregiver involvement has been shown to influence dietary intake in people with ID. Adolfsson et al⁵⁵ found that more meals were prepared with fresh ingredients when caregivers were involved and gave recommendations to the participants preparing the meals as opposed to participants preparing meals with no supervision. Fresh fruit and vegetable intake was highest when caregivers were involved in meal preparation.⁵⁵ However, although intake was considerably lower, total calorie and saturated fat intake was highest when caregivers were in control of

TABLE 7 Healthcare/Screening Guidelines for Adults With Down Syndrome ^{42,56}					
The National Down Syndrome Society	The American Academy of Pediatrics				
Thyroid function tests (annual)	Thyroid function tests (annual)				
Auditory tests (every 2 y)	Auditory tests (annual)				
Cervical spine x-rays (as needed for sports)	Discuss risk of spinal cord injury with some sports				
Eye examinations (every 2 y)	Ophthalmologic evaluation (every 3 y)				
Echocardiogram (as indicated)	Cardiology follow-up (based on history of cardiac defects)				
General physical/neurological examination	Monitor for signs of neurologic dysfunction				
Obesity monitoring with emphasis on low-calorie, high-fiber diet	Monitor growth patterns and body mass index; counsel on healthy diets and exercise				
Evaluation for sleep apnea	Evaluation for sleep apnea				
Evaluation of functional abilities and behavioral/emotional/ mental health	Discuss behavioral and social issues				
Mammography (baseline at age 40 y); breast examination (annually)	Hemoglobin test (annual)				
Abuse-prevention and sexual education	Monitor for symptoms potentially related to celiac disease				
	Assess, monitor, and encourage independence with hygiene and self-care				
	Discuss issues related to adulthood; eg, financial planning, residential settings, and morbidities such as premature aging				

the participants' meal preparation, suggesting that caregiver education is still an important factor in obesity.⁵⁵

Health Screening and Management

Primary care physicians should prioritize persons with DS as they conduct standard health/wellness protocols and not bypass people with DS or make exceptions because of the person's ID. Health screenings may be provided by physicians or other organizations dedicated to people with ID and should incorporate current guidelines (Table 7).⁵⁷ Although there are many screening tools and monitoring guidelines, many people with ID receive suboptimal care.⁵⁷ Health professionals should actively reach out to this underserved population and offer routine health screenings and/or care through various venues and organizations. The Special Olympics, for example, offers health screenings in 7 areas through their Healthy Athletes programs: Fit Feet (podiatry), FUNfitness (physical therapy), Health promotion (nutrition, health, an well-being), Healthy Hearing (audiology), MedFest (sports physical examination), Opening Eyes (vision), and Special Smiles (dentistry).⁵⁷

CONCLUSION

Although people with DS have some physiological conditions that predispose them to excess body fatness, present research implicates that most of the excess weight is more heavily influenced by environmental factors. Knowledgeable dietitians who understand the challenges that people with DS face are important resources for addressing the weight issue in people with DS. Education of people with DS and their caregivers on nutrition and healthful eating is a critical aspect of weight maintenance and must be tailored to their individual needs.

Further research is needed on overcoming the barriers to maintaining healthy weight and nutrition status that stratifies data by the level of ID and setting. Energy needs should be estimated for people with DS. Recommendations must be individualized to each person and at each level of care starting in childhood and continue through adulthood. Lastly, awareness needs to be raised among the community, and the medical community needs to recognize and aggressively address the health issues that occur with this population. Adults with DS who learn to live healthier lives lighten their caregivers' burdens and can hopefully contribute more to society.

REFERENCES

- 1. Allt J, Howell C. Down's syndrome. Br J Anaesth. 2003;3(3):83-86.
- Kliegman R, Stanton B, St. Geme J, Schor N, Behrman R. Down syndrome. In: *Nelson Textbook of Pediatrics*. 19th ed. Philadelphia, PA: Elsevier Saunders; 2011:400–402. Accessed February 22, 2013.

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- Balarajan R, Donnan S, Adelstein A. Mortality and cause of death in Down's syndrome. *J Epidemiol Community Health*. 1982;36(2):127–129.
- 4. Bittles AH, Bower C, Hussain R, Glasson EJ. The four ages of Down syndrome. *Eur J Public Health.* 2007;17(2):221–225.
- Braunschweig CL, Gomez S, Sheean P, Tomey KM, Rimmer J, Heller T. Nutritional status and risk factors for chronic disease in urban-dwelling adults with Down syndrome. *Ment Retard*. 2004;109(2):186–193.
- Associated conditions. National Down Syndrome Society Web site. http://www.ndss.org/Resources/Health-Care/Associated-Conditions/. Updated 2012. Accessed February 22, 2013.
- Cooper SA, Melville CA, Morrison J. People with intellectual disabilities—their health needs differ and need to be recognised and met. *Br Med J.* 2004;329:414–415.
- Defining overweight and obesity. http://www.cdc.gov/obesity/ adult/defining.html. Published April 27, 2012. Updated 2012. Accessed February 22, 2013.
- Melville C, Cooper SA, Morrison J, Allan L, Smiley E, Williamson A. The prevalence and determinants of obesity in adults with intellectual disabilities. *J Appl Res Intellect Disabil.* 2007;21(5):425–437.
- Bell AJ, Bhate MS. Prevalence of overweight and obesity in Down's syndrome and other mentally handicapped adults living in the community. *J Intellect Disabil Res.* 1992;36:359–364.
- Stewart L, Beange H, Mackerras D. A survey of dietary problems of adults with learning disabilities in the community. *Ment Handicap Res.* 1994;7:41–50.
- 12. Prasher V. Overweight and obesity amongst Down's syndrome adults. J Intellect Disabil Res. 1995;39(5):437–441.
- 13. Fujiura GT, Fitzsimons N, Marks B, Chicoine B. Predictors of BMI among adults with Down syndrome: the social context of health promotion. *Res Dev Disabil.* 1997;18(4):261–274.
- Rubin SS, Rimmer JH, Chicoine B, Braddock D, McGuire DE. Overweight prevalence in persons with Down syndrome. *Ment Retard.* 1998;36:175–181.
- Rimmer JH, Wang E. Obesity prevalence among a group of Chicago residents with disabilities. *Arch Phys Med Rehabil.* 2005; 86(7):1461–1464.
- Rimmer J, Yamaki K, Lowry B, Wang E, Vogel L. Obesity and obesityrelated secondary conditions in adolescents with intellectual/ developmental disabilities. *J Intellect Disabil Res.* 2010;54(9):787–794.
- Bandini L, Fleming R, Scampini R, Gleason J, Must A. Is body mass index a useful measure of excess body fatness in adolescents and young adults with Down syndrome? *J Intellect Disabil Res.* 2013; 57(11):1050–1057.
- Prasher V. Down syndrome and thyroid disorders: a review. Down Syndr Res Pract. 1999;6(1):25–42.
- 19. Coleman M. Thyroid dysfunction in Down's syndrome: a review. *Down Syndr Res Pract*. 1994;2(3):112–115.
- Kelly TL, Wilson KE, Heymsfield SB. Dual energy X-ray absorptiometry body composition reference values from NHANES. *PLoS One.* 2009;4(9):e7038.
- Chad K. Metabolic rate: a factor in developing obesity in children with Down syndrome? Am J Ment Retard. 1990;95(2):228–235.
- 22. Draheim CC, Stanish HI, Williams DP, McCubbin JA. Dietary intake of adults with mental retardation who reside in community settings. *Am J Ment Retard*. 2007;112(5):392–400.
- Chapter 7: Additional considerations for some adults. US Department of Health and Human Services Web site. http://www.health.gov/paguidelines/guidelines/chapter7.aspx. Updated 2008. Accessed February 22, 2013.
- Draheim CC, Williams DP, McCubbin JA. Prevalence of physical inactivity and recommended physical activity in community-based adults with mental retardation. *Ment Retard*. 2002;40(6):436–444.
- Pueschel SM. Clinical aspects of Down syndrome from infancy to adulthood. Am J Med Genet. 2005;37(S7):52–56.
- Yamaki K. Body weight status among adults with intellectual disability in the community. *Ment Retard*. 2005;43(1):1–10.

- de Winter CF, Bastiaanse LP, Hilgenkamp TIM, Evenhuis HM, Echteld MA. Overweight and obesity in older people with intellectual disability. *Res Dev Disabil.* 2012;33:398–405.
- Jobling A, Cuskelly M. Young people with Down syndrome: a preliminary investigation of health knowledge and associated behaviours. *J Intellect Disabil Res.* 2006;31(4):210–218.
- 29. de Winter CF, Bastiaanse LP, Hilgenkamp TIM, Evenhuis HM, Echteld MA. Cardiovascular risk factors (diabetes, hypertension, hypercholesterolemia and metabolic syndrome) in older people with intellectual disability: results of the HA-ID study. *Res Dev Disabil.* 2012;33:1722–1731.
- Leading Causes of Death (Data are for the US). Centers for Disease Control and Prevention Web site. http://www.cdc.gov/nchs/ fastats/lcod.htm. Published January 27, 2012. Updated 2013. Accessed August 5, 2013.
- Mann J, Zhou H, McDermott S, Poston MB. Healthy behavior change of adults with mental retardation: attendance in a health promotion program. *Ment Retard*. 2006;111(1):62–73.
- 32. Rimmer JH, Yamaki K. Obesity and intellectual disability. *Ment Retard Dev Disabil Res Rev.* 2006;12(1):22–27.
- 33. Kirkpatrick SI. Understanding and addressing barriers to healthy eating among low-income Americans. *J Acad Nutrition Diet*. 2012;112(5):617–620.
- Tracy J. Intellectual disability. Centre for Developmental Disability Victoria Web site. http://cddh.monash.org/assets/documents/ intellectual-disability-1.pdf. Accessed April 29, 2014.
- 35. Graf C. The Lawton Instrumental Activities of Daily Living (IADL) Scale. Try this: Best Practices in Nursing Care to Older Adults. New York, NY: The Hartford Institute for Geriatric Nursing, New York University, College of Nursing; 2013; No. 23.
- 36. D'Angelo H, Suratkar S, Song HJ, Stauffer E, Gittelsohn J. Access to food source and food source use are associated with healthy and unhealthy food-purchasing behaviours among low-income African-American adults in Baltimore City. *Public Health Nutrition*. 2011;14(9):1632–1639.
- Barr M, Shields N. Identifying the barriers and facilitators to participation in physical activity for children with Down syndrome. *J Intellect Disabil Res.* 2011;55(11):1020–1033.
- Traci MA, Seekins T, Szalda-Petree A, Ravesloot C. Assessing secondary conditions among adults with developmental disabilities: a preliminary study. *Ment Retard*. 2002;40(2):119–131.
- Wisniewski KE, Wisniewski HM, Wen GY. Occurrence of neuropathological changes and dementia of Alzheimer's disease in Down's syndrome. *Ann Neurol.* 1985;17:278–282.
- Koritsas S, Iacono T. Limitations in life participation and independence due to secondary conditions. *Am J Intellect Dev Disabil.* 2009;114(6):437–448.
- Lashno M. Sensory integration: observations of children with Down syndrome and autistic spectrum disorders. Kennedy Krieger Institute Web site. http://www.kennedykrieger.org/patient-care/ outpatient-programs/sensory_integration. Updated 1999. Accessed March 25, 2013.
- Bull MJ. Health Supervision for Children with Down Syndrome. *Pediatrics*. 2011;128(2):393–406.
- 43. Carmeli E, Kessel S, Merrick J, Bar-Chad S. A comparison between older persons with Down syndrome and a control group: clinical characteristics, functional status and sensori-motor function. *Down Syndr Res Pract.* 2004;9(1):17–24.
- 44. Capone G, Muller D, Ekvall SW. Down syndrome. In: Ekvall S, Ekvall V, eds. *Pediatric Nutrition in Chronic Diseases and Developmental Disorders: Prevention, Assessment, and Treatment.* New York, NY: Oxford Press; 2005:121–132.
- Kusters MAA, Verstegen RHJ, Gemen EFA, de Vries E. Intrinsic defect of the immune system in children with Down syndrome: a review. *Clin Exp Immunol.* 2009;156(2):189–193.
- Medlen JEG. The Down Syndrome Nutrition Handbook: A Guide to Promoting Healthy Lifestyles. Portland, OR: Phronesis Publishing, LLC; 2006.

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- Mahoney G, Perales F, Wiggers B, Herman B. Responsive teaching: early intervention for children with Down syndrome and other disabilities. *Down Syndr Res Pract*. 2006;11(1):18–28.
- Nilholm C. Early intervention with children with Down syndrome—past and future issues. *Down Syndr Res Pract.* 1996; 4(2):51–58.
- Elinder LS, Bergström H, Hagberg J, Wihlman U, Hagströmer M. Promoting a healthy diet and physical activity in adults with intellectual disabilities living in community residences: design and evaluation of a cluster-randomized intervention. *BMC Public Healtb.* 2010;10(1):761.
- Hamilton S, Hankey C, Miller S, Boyle S, Melville C. A review of weight loss interventions for adults with intellectual disabilities. *Obes Rev.* 2007;8(4):339–345.
- Marshall D, McConkey R, Moore G. Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *J Adv Nurs.* 2003;41: 147–153.
- 52. Fox RA, Rosenberg R, Rotatori AF. Parent involvement in a treatment

program for obese retarded adults. *J Behav Ther Exp Psychiatry*. 1985;16(1):45–48.

- 53. Lunsky Y, Straiko A, Armstrong S. Women be healthy: evaluation of a women's health curriculum for women with intellectual disabilities. *J Appl Res Intellect Disabil.* 2003;16(4):247–253.
- Melville CA, Hamilton S, Miller S, et al. Carer knowledge and perceptions of healthy lifestyles for adults with intellectual disabilities. *J Appl Res Intellect Disabil.* 2009;22(3):298–306.
- Adolfsson P, Fjellström C, Lewin B, Sydner YM. Foodwork among people with intellectual disabilities and dietary implications depending on staff involvement. *Scand J Disabil Res.* 2012;14(1):40–55.
- 56. Down syndrome health care guidelines. National Down Syndrome Society Web site. http://www.ndss.org/Resources/Health-Care/Health-Care-Guidelines/Adult-Health-Care-Guidelines/. Updated 2012. Accessed May 1, 2013.
- 57. Providing health services worldwide for the most underserved. Special Olympics Web site. http://www.specialolympics.org/ Sections/What_We_Do/Healthy_Athletes/Health_Programs .aspx. Accessed March 21, 2013.

Editor's note: Readers should remember that there is so much variability in Down syndrome individuals in terms of the role of lifestyle and diet's contributions that it is important to work closely with medical experts to ensure that interventions are appropriate for each person's situation. Also, although beyond the scope of this article, the importance of fitness and physical activity should be emphasized.