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**An Analysis of Nutritional Services Available for Persons with
Developmental Disabilities**

by

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**Thesis submitted in partial fulfillment
of the requirements for the degree**

of

DEPARTMENT HONORS

in

Nutrition and Food Sciences

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2006

An Analysis of Nutritional Services Available for Persons with Developmental Disabilities

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Keywords: developmental disabilities; nutrition; obesity; community programs

Word Count:

Abstract: 140

Text: 2,381

An Analysis of Nutritional Services Available for Persons with Developmental Disabilities

ABSTRACT

Developmental disabled (DD) individuals are living longer, more normal lives in the United States. There has been an influx of DD individuals living in residential settings instead of the more traditional institutional setting. Consequently, dietetic professionals will encounter persons with DD in every area of practice. Nutrition therapy is becoming more important in the multidisciplinary treatment of DD individuals. Governmental legislation and community programs have improved the treatment and rights of DD persons over the past decade. Even with these advocacy efforts, DD persons are often not receiving the nutritional treatment they need. Common nutritional problems encountered in the DD population include obesity and related conditions, feeding difficulties, and residential dietary management. Future efforts of dietetic professionals need to focus on promoting the necessity of nutritional services. Through these efforts, the nutritional status of the DD population can be improved.

An Analysis of Nutritional Services Available for Persons with Developmental Disabilities

INTRODUCTION

Due to the advancement of medical technology over the past decade, there has been an increase in the number of individuals with developmental disabilities who survive into adulthood (1). It is estimated that ninety percent of developmentally disabled (DD) children survive into adulthood (1). Over the past forty years, awareness and acceptance for DD persons has increased, resulting in the mainstreaming of these individuals into the general population. Consequently, dietetic professionals will encounter persons with DD in every area of practice (2). The American Dietetic Association, a professional organization for dietetic professionals, has recognized the importance of nutritional services in individuals with DD (2, 3).

The purpose of this paper is to examine the nutritional status, problems, and interventions in place for the DD population. A discussion of governmental support, community involvement, and current nutrition services available is necessary to evaluate the nutritional status of the DD population and to suggest future programs and improvements for the enhancement of their nutritional status.

DEFINING THE POPULATION

Developmentally disabled individuals constitute a broad population, including more than forty different disability conditions. Disabilities vary in physical, developmental, and cognitive functions and abilities (1, 4). Consequently, it is difficult to

determine the prevalence of DD; however, it has been estimated that mental retardation has a prevalence of 1-2% in the United States (1). An estimated 3 to 4 million Americans have a DD, and an additional 3 million have a milder form of cognitive dysfunction (3). The Centers of Disease Control recently released a prevalence of DD at 3.8 million children and youth (1).

The United States Government defines developmental disabilities as subaverage mental function, occurring concurrently with two or more of the following limitations: communication, self-care, functional academics and home-living community use, self-direction, health and safety, leisure, work and social skills (3). DD limitations must be manifested by the age of 18 and continue indefinitely.

DD have many etiologies, including chromosomal abnormalities, congenital anomalies, inherited metabolic disorders, traumatic incidents, and other unknown origins. Persons may have more than one condition, further compounding the complex situation and increasing the need for multidisciplinary approaches in treatment (3, 5).

DD individuals often have conditions that put them at nutrition risk (3). Unfortunately, because of the complex difficulties that this population encounters, nutrition-related problems and issues are not the priority and often go untreated (4).

LEGISLATION

Recent legislation has led to the improved understanding and treatment of DD individuals. Before the 20th century, DD individuals were cared for mainly by institutions in cruel and unmonitored conditions (2). Common problems included malnutrition, a low

staff-to-patient ratio, and a lack of nutrition services (2). A class action suit in the 1970s, known as the Wyatt-Stickney case, resulted in the enactment of treatment standards that improved nutrition services in institutions, including improved manpower ratios and nutrition standards for meals. Also during the 1970s, the government was focused on deinstitutionalization; consequently, DD residents were pushed toward group homes and other independent living situations, which is currently the situation for most DD individuals (2). Dietitians are sometimes, but not often enough, consultants for nutrition services in these facilities. Nutritional consequences of deinstitutionalization followed and increased the DD population's nutrition risk.

The first legislation passed by the United States government for DD individuals was the Developmental Disabilities Assistance and Bill of Rights Act of 1963 (3). This act defined disabilities, provided advocacy systems, and included specialized nutrition training for university students for career preparation (2, 3). Further revisions and additions of this act were enacted throughout the following decades. In 2000, the act was revised (3). This edition supports advocacy for DD individuals and provides aid to individuals and their families to find the information they need to live healthier, longer lives. This act continues to promote the affiliation of university programs and training courses for students and community members in DD treatment and care (3).

Other community programs that have been instituted to aide DD persons include Head Start, a government-mandated program, requires 10% that of total enrollment to be disabled children (2, 3). Head requires that a Registered Dietitian provide nutrition services to the program participants. Other community programs reaching out to DD

individuals include the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), the School Lunch and Breakfast Program, the Department of Services for People with Disabilities, and several other programs not mentioned (2, 3).

Even with all the above-mentioned governmental action and community programs, many DD individuals' healthcare needs are not being met. An analysis of the accessibility of primary and preventive services found that 4% of DD children were not covered by health insurance and were therefore unable to get their medical needs met (1). In the same study, nutrition therapy services were addressed. Of the seventy-five participants with nutritional concerns, only three were referred for nutrition therapy, while the remaining seventy-two continued with unaddressed nutrition concerns (1). Participants identified multiple barriers for nutrition referrals, including lack of information, lack of available services, lack of concern from the medical professional, lack of family priority, lack of transportation, or other nonspecified barriers. Similar findings were found in other multidisciplinary areas, such as behavior management/counseling, speech therapy, and dental services (1). Community-based programs, including two programs mentioned above, WIC and Head Start, also had low accessibility and therefore low participation by DD individuals. A suggested reason for this low participation rate is a lack of referral by other health professionals (1).

As a result of low nutrition therapy referrals and low community-based program participation rate, DD individuals encounter many untreated nutrition-related health problems (1, 3).

NUTRITION-RELATED PROBLEMS

In a research study examining feeding disorders among DD individuals, results indicate that nutrition interventions significantly improved energy consumption and overall nutritional status (6). Morbidity also decreased in subjects through appropriate nutrition interventions (6). This study stresses the importance of nutrition services for DD persons. There are many nutrition-related issues present in the population, including obesity, feeding difficulties, and residential dietary management.

Obesity

The incidence of obesity among Americans has increased dramatically and has been termed an “epidemic” (4). In an observational study, using the National Health and Nutrition Examination Survey (NHANES) 1999-2000 data, researchers identified the rate of DD persons with obesity (4). Unfortunately, difficulties arise in assessing the incidence of obesity in this population because of the broad range of developmental disorders. For example, there is a high rate of obesity in certain conditions, such as Down syndrome and Prader-Willi, but a lower rate in boys with attention-deficit disorder (3, 4). However, in the overall DD population, researchers found that individuals with DD have a similar prevalence of overweight as the normal population (4). This is of consequence because the normal population has a high rate of overweight and obesity, indicating a great need for health and nutrition promotion efforts among dietetic professionals (4).

Proposed reasons for the high rate of obesity incidence among DD individuals include a lack of participation in physical activities because of poor coordination, social

isolation, and/or exclusion from team sports (4). Additionally, many caregivers use food as a behavior reinforcer which can lead to a positive energy balance and weight gain (4).

Oftentimes, weight control is not a priority in this population. DD persons are burdened by multiple, complex problems that require the involvement of multiple professionals and disciplines (7). Consequently, weight control and obesity lose priority to other pressing issues.

A consequence of obesity in the DD population is the occurrence of associated diseases, such as diabetes, high blood pressure, cardiovascular disease, and stroke (8). These issues are also treatable and, more importantly, preventable through appropriate medical nutrition therapy. Nutrition therapy is critical in decreasing morbidity and mortality in individuals with DD (8).

Feeding Difficulties

Feeding difficulties can range from mild food allergies to severe chewing and swallowing problems. Unfortunately, many DD individuals have at least one form of feeding difficulty. Feeding dysfunction is related to decreased growth and poor nutrition intake among children (3, 9). A lack of self-feeding skills increases mortality six-fold (3). In some patients, tube feeding may even be required on a continual basis to prevent growth failure and malnutrition. Many children and adults with DD depend on caregivers to feed them daily; therefore, it is imperative that dietitians and caregivers evaluate clients' nutritional status often to assess adequacy of the nutrition provided (3).

Proper nutrition therapy interventions can prevent a decline in nutritional status among DD individuals (3, 6). A structured approach in treating feeding disorders can

significantly decrease morbidity and lead to successful management of feeding problems (6).

Residential Dietary Management

Over the past twenty years, the number of DD individuals who living in community residences has increased (10). The community homes are managed by a staff team, who may or may not have professional nutrition training (10). While group homes have many beneficial aspects for the DD population, including increased independence, there are often problems in dietary management. In institutional settings, the meal planning, preparation, and other food practices are carried out by trained professionals and staff, whereas in group homes, the responsibility falls to staff members who are consumers themselves. The lack of staff training can lead to a poor dietary intake among DD individuals and lead to detrimental effects, including obesity and related conditions, low nutrient-dense diet, and overall increased morbidity (6, 10).

In a study conducted on care providers in community-based group homes, researchers found that effective staff training could increase the nutritional status of DD clients (10). The study trained thirteen care providers in three one-hour sessions on topics such as proper food storage, menu development, and meal preparation. Results indicated that post-training, correct food storage increased from 54% to 89%, menu development increased from 28% to 81%, and meal preparation from 37% to 92%. Adherence to the Recommended Dietary Allowances also increased post-training in the DD clients. DD clients also reduced their body weight, serum cholesterol, and blood pressure as a result of staff training efforts (6). The results were significant in proving the effectiveness of staff

training. Researchers concluded that training staff in nutritional practices is a huge step toward quality-of-life enhancements for people with disabilities in community settings (6).

CURRENT ROLES OF REGISTERED DIETITIANS

The role of dietetic professionals with DD individuals includes working as a member of an interdisciplinary team. The team should include a physician, nurse, direct-care staff, social worker, and/or other necessary specialists (2, 3). The dietitian is responsible for assessing the overall nutritional status of the individual, including anthropometric, biochemical, clinical, and dietary measures of the individuals. There must be a focus on individual dietary construction, which allows the dietetic professional to prevent common problems associated with DD. For example, malnutrition, dysphagia, and delayed growth are common and should be addressed immediately.

Other responsibilities include training family and/or staff members on proper dietary practices and management (3, 10). Studies show that training direct-care providers on dietary issues increases the DD clients' overall nutritional status and improves nutrient intake (10). Dietitians also may need to educate other professionals, including fellow dietitians, on working specifically with DD individuals (3).

Outside of medical nutrition therapy, advocacy for this less-represented population is necessary for the increase of nutrition therapy referrals by physicians and other health care providers (3). Research and continued education is needed for dietitians in the DD area. As the size of the population increases over the next century, more dietitians will be needed to promote the health and well-being of DD individuals (3).

FUTURE IMPROVEMENTS

The mission statement of the Department of Services for People with Disabilities, a government backed program and major advocate for DD individuals, is “to promote opportunities and provide supports for persons with disabilities to lead self-determined lives” (11). One of their main values is “we believe people deserve high quality supports and services” (11). Nutrition services are an important part of “supports and services.” To provide DD persons with the optimal nutrition support, much more needs to be done to improve the accessibility and provision of services.

According to the American Dietetic Associations Position Statement (2004), there are no medical nutrition protocols set up for providing nutrition services to the DD population (3). General medical nutrition therapy for the normal population is currently the standard for dealing with DD individuals; however, general guidelines are not specifically meant for this population. Developing protocols for working with the DD population would be a large step toward increasing the amount and quality of nutrition services provided (3). Currently a dietetic practice group in the American Dietetic Association specializes in providing services for DD individuals (12). This group will be important in increasing awareness and treatment guidelines among Registered Dietitians. One of their major goals is “the inclusion of course work and practicum experiences in DD in the education of dietetic practitioners” (12).

Another area for future improvement in nutrition services includes the support of dietitians in programs that promote the health for persons with DD. Support from

nationally credentialed professionals, such as registered dietitians, increases the programs chances of obtaining funding and further success.

Educating other health care providers on the importance of including nutrition services in interdisciplinary teams and treatment is imperative (3). Education will increase referral rates by physicians for nutrition therapy, because, as stated previously, a majority of DD individuals are not being referred to nutrition therapy (1).

Further promotion efforts by Registered Dietitians are crucial for the nutritional status of the DD population. Through advocacy, support, and further education, nutrition professionals can play a key role in improving the health and wellbeing of DD individuals. As the number of DD individuals rises, future efforts will ensure success.

CONCLUSION

Treating DD individuals is a complex process that involves a multidisciplinary approach (1), including nutrition therapy. Nutrition therapy has been shown to treat and prevent many nutrition-related problems in the DD population. Unfortunately, many DD individuals are not receiving the care they need (1).

A goal of the Department of Services for People with Disabilities is to “promote public awareness of disability issues and to support a full spectrum of service options” (11). Increasing awareness among healthcare providers and the community will, hopefully, indirectly play a role in improving the accessibility of nutrition services. Dietitian support in the advocacy of DD individuals is imperative for the improved nutritional status of this population.

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