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Nutrition and Disability

A disability often can be complicated by additional medical, psychological, or environmental problems. Under an emerging framework of health promotion for persons with disabilities, these additional health problems are referred to as *secondary conditions* (Brandt & Pope, 1997; Marge, 1988; Pope & Tarlov, 1991). Until recently, it was common to conceptualize these ailments as symptomatic of the primary disability; however, it is now presumed that because these conditions can be prevented or managed, they are secondary conditions distinct from the primary disability.

Although information on secondary conditions experienced by people with developmental disabilities is limited, the literature does contain descriptions of some risk factors (Eyman, Chaney, Givens, Lopez, & Lee, 1986); identification of various diseases as sources of later, additional limitation (Miller & Eyman, 1979); and suggested health practices that might lead to the prevention of some secondary conditions (e.g., Marge, 1988).

This research progress report describes three significant nutrition-related risk factors for secondary conditions in people with developmental disabilities—malnutrition, obesity, and issues related to the support staff responsible for food planning and preparation. These risk factors have potential to respond positively to improved health practices through well-considered interventions.

Background

Nutrition is related to secondary conditions in persons with developmental disabilities in four significant ways.

1. Nutrition may be viewed as a risk factor for secondary conditions. (Poor nutrition, nutritional status, or eating habits make the secondary condition worse.)
2. Nutrition can be a protective factor. (Good nutrition, nutritional status, or eating habits can improve the secondary condition.)
3. Poor nutrition in the form of deficiencies can be a secondary condition itself.
4. Many secondary conditions can further modify one's diet and create subsequent nutritional problems.

Malnutrition

Malnutrition encompasses both under-nutrition and over-nutrition that lead to negative anthropometrical, biochemical, or clinical outcomes for an individual. Nutrition was investigated in our 1999 universal survey of adult consumers of Montana's Developmental Disability Program (DDP) services; survey items were included to help determine nutrition as a risk factor, a protective factor, or a secondary condition.

Poor nutrition may be a risk factor in this population for the following observed secondary conditions:

Weight problems
 Bladder dysfunction
 Fatigue
 Bowel dysfunction
 Depression
 Physical fitness/conditioning problems
 Dental/oral hygiene problems
 Sleep problems/disturbances

...and may be a risk factor for the following possible or identified medical secondary conditions:

Gastrointestinal dysfunction
 Urinary tract infections
 Side effects from medications
 Allergies and allergic reactions
 Cardiovascular/circulatory problems
 Diabetes
 Osteoporosis
 Nutritional deficits
 Cancer

Many of the secondary conditions listed above are associated with under-nourishment or over-nourishment in the general U.S. adult population. Over-nourishment includes consumption of nutrients in a pattern that leads to the development of such diseases as cardiovascular disease, cancer, or diabetes. Under-nourishment precipitates nutrient deficiencies leading to such conditions as anemia, osteoporosis, or wasting in adults.

Over-nutrition

It may be that the most compelling nutrition issues for adults with developmental disabilities are the same ones affecting the general U.S. adult population. In our attempts to measure and assure adequacy in these diets, nutrition researchers have set aside the more relevant

problem of abundance that encourages over-nutrition and leads to chronic disease.

Over-consumption of total fat, saturated fat, and cholesterol is associated with an increased risk of obesity, as well as cardiovascular disease, some cancers, diabetes, and other chronic diseases. In general, the largest contributor of fat in the American diet is added oils and fats in the form of baked goods, salad dressings, candies, gravies, sauces, fried foods, and high fat snack foods.

A recent review of the grocery receipts, menus, and the pantry contents of three Montana living facilities for people with developmental disabilities showed that higher fat meats and other foods are available in amounts beyond those recommended for good health. Interviews indicated that consumers consider many of these foods highly desirable. Pizza is a favorite; luncheon meat is a staple product; hot dogs and *Hot Pockets*—processed meat and cheese in a high fat crust—are all consumed regularly; TV dinners are popular.

Such preferences may have evolved into well-established **food traditions**. Food traditions in a residence include what foods the consumers have grown accustomed to preparing and eating over the years, and what food-related skills and methods are passed down from experienced staff members to new ones. Tradition that is firmly set can serve as a barrier, even to the most skilled and experienced consumers and service staff, in attempts to improve nutrition.

Under-nutrition

Underweight and maintaining weight can present problems for some adults with developmental disabilities (*ADA Position Paper*, 1997). Feeding problems arising from neuromuscular dysfunction and distracting behavior tend to be more problematic for children's nutrient intake (Springer, 1987; Pesce, 1989; Gouge, 1975). For example, cerebral palsy is associated with underweight and under-nutrition in children who experience difficulties in swallowing, chewing, or sucking due to partial paralysis of facial, tongue,

and pharyngeal muscles (Sanders et al., 1990).

These problems may not be entirely resolved in the adult, but are most often addressed through specialized diets, therapies, and other supports. In children with developmental disability, poor nutrition is considered a risk factor for secondary learning problems, which can be expected to further affect their development (Ault, Guy et al., 1994). Poor nutrition is not considered a risk factor for learning problems in adults, but this has not been examined adequately.

Persons with developmental disabilities are more likely to be taking prescribed medication for seizure tendencies, chronic infections, gastrointestinal problems, and poor circulation. Any of the common medications prescribed for these conditions, taken under particular circumstances (e.g., long-term use, in combination with other drugs) could affect the nutritional status of an individual (W. Docktor, personal interview, June, 2001). Various medications can affect food intake through side effects such as changes in the sense of taste, decreases or increases in appetite, dry mouth, or nausea.

Obesity

Obesity can be a condition secondary to the primary developmental disability and is an example of a condition that can lead to subsequent limitations. Obesity in the general population contributes to premature death, heart disease, diabetes, cancer, breathing problems, arthritis, reproductive complications, gall bladder disease, incontinence, increased surgical risk, and depression (Surgeon General *Call to Action*, 2002).

While to date little research has been done to show the same result in adults with developmental disabilities, there is no information that indicates a different effect. Further, the Surgeon General's report states, "Obesity can affect the quality of life through limited mobility and decreased physical endurance as well as through social, academic, and job discrimination." For a population at risk

for decreased mobility and physical endurance already, further stress on those quality of life indicators through obesity has an even greater potential impact.

A high prevalence of obesity in adults with developmental disabilities has been recorded in both institutional and community settings (Cunningham et al., 1990; Warpula, 1981; Stewart, 1994). Data from the most recent administration of the *Inventory for Client and Agency Planning* (Bruinicks, Hill, Weatherman, & Woodcock, 1986) show the rates of overweight (Body Mass Index [BMI]>25) and obesity (BMI>30) to be 55% and 26% respectively for adults with developmental disabilities in Montana. Obesity in persons with developmental disabilities is attributed to behavioral factors such as inappropriate eating practices and limited mobility (*ADA Position Paper*, 1997) though environmental factors contributing to high rates of overweight and obesity in the general U.S. population may be important as well.

Some studies have suggested that nutritional and physical activity interventions might help prevent the development of obesity and lessen the effects of atypical body composition caused by excess adipose tissue (Shepherd et al., 1991). A program for weight management for a person with a developmental disability must address individual characteristics of motivation, food preferences, metabolic individuality, mobility, and feeding problems, as well as environmental contributors to overweight and obesity, just as a weight management program for a person without a developmental disability must address these issues.

Staffing Issues

In assisted living situations, staff members act as gatekeepers for foods entering the households; they often influence consumer choice or directly control how to plan and prepare the food. They facilitate access to snacks and foods that are not on the menus. Group home directors and direct service staff indicated in interviews with us that dietary quality among consumers is influenced

by the behavior of the staff members who interact with them during meal and menu planning, grocery list generation, grocery shopping, meal preparation, and meal and snack service. For example, a direct service staff member preparing a meal of chicken and potatoes for eight residents has the latitude to cook the food in any manner he judges appropriate. "Chicken and potatoes" on the menu could mean breaded, fried chicken with home fries or it could mean a lower fat meal of roasted chicken with baked potatoes.

Interviews also revealed that staff members who are *not* responsible for food planning, shopping, etc., can actually undercut health-oriented efforts of the person who *is* responsible. For example, as part of a goal to reduce fat and sweets, a staff member may be monitoring and limiting how much ice cream is purchased and consumed in the household. If such goals are not explicit, staff members on other shifts might go to the grocery store and purchase more ice cream because the house "ran out."

Staff turnover can prove to be a barrier to improved nutrition. High turnover rates among staff prohibit extensive training and experience in food responsibilities. In addition, stable, individualized, and healthful food habits are created over time using a long-term plan. This is difficult to achieve with unstable staffing.

Suggestions for Change

➔ Including a dietician on the treatment/support team has been shown to improve the nutritional status of children in an institutional setting (Hogan & Evers, 1997). This finding may well have application for adults with developmental disabilities who live in an institutional setting, as well as for adults who live in community-based settings that utilize a support staff.

➔ Litchford and Wakefield (1985) found that a short program of nutrition education for direct service staff in an institutional setting improved consumers' intake of several key nutrients.

➔ At The University of Montana Rural Institute,

we have drafted a tri-level standard of care to provide nutritional adequacy for persons with developmental disabilities. It includes individualized programs where needed and focuses on wellness wherever possible. This standard of care is currently in review by nutritionists, human development specialists, consumers and their families, and supported-living staff.

Future areas of research

Directions for future research in nutrition at The University of Montana Rural Institute include:

- A comprehensive and well-designed study of the actual food intake of people with developmental disabilities who live in group homes and in semi-independent living situations.
- An inquiry into the risk factors, physiological responses, nutrient requirements, and food intake patterns of adults with developmental disabilities, followed by comparison with the U.S. general adult population.
- A test of the assumption that good menu planning will necessarily yield better nutrition. One staff member who directs the cooking and meal service for many meals at one Montana assisted living home reports making numerous last minute additions and deletions to the menus. Do these changes make the actual meals better or worse nutritionally?
- An effectiveness study of which nutrition interventions provide the most health benefit to the most consumers.
- An investigation of healthy aging with a disability, including how to maintain an adequate diet into late adulthood.

It is critical for the health and wellness of persons with developmental disabilities that the excellent nutrition research being conducted in the general population be extended to their population as well.

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Resources

Food and Nutrition Information Center, National Agricultural Library, U.S. Department of Agriculture, ARS, 10301 Baltimore Avenue, Room 304, Beltsville, MD 20705-2351; <http://www.nal.usda.gov/fnic/>. Provides information on nutrition and food safety.

Surgeon General Call to Action (2002). Available at: <http://www.surgeongeneral.gov/topics/obesity/>.

Healthy People 2010, Office of Disease Prevention and Health Promotion, HH Humphrey Bldg., Rm 738G, 200 Independence Avenue, S.W., Washington, DC 20201. www.health.gov/healthypeople/. This is a set of national health objectives for the first decade of the new century.

Information on disability and secondary conditions is available at:
<http://www.health.gov/healthypeople/document/html/volume1/06disability.htm>.

Prader-Willi Syndrome Association, 5700 Midnight Pass Rd., Sarasota, FL 34242; 800-926-4797. <http://www.pwsausa.org>. Provides a network of information, support services, and research to meet the needs of children and adults affected by this genetically-based developmental disability.

Food and Drug Administration Center for Food Safety and Applied Nutrition, <http://vm.cfsan.fda.gov/~lrd/advice.html>. Offers consumer advice on food safety and products.

Tufts University Health Sciences Library. http://www.library.tufts.edu/hsl/hsl_nutr_resources.html. Provides a guide to nutrition resources on the Internet, including links to health letters, journals, and nutrition associations.

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