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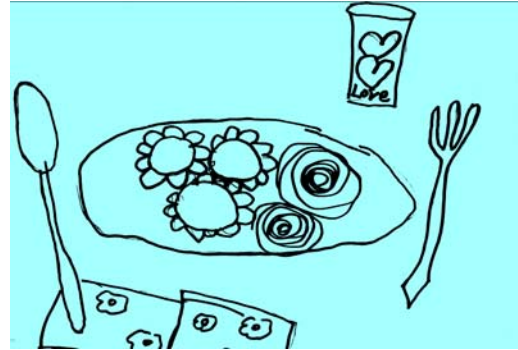
# Nutrition for Individuals with Intellectual or Developmental Disabilities

## ***Nutrition Standards of Care***

for Use by Personal Assistants, Service Providers, Healthcare Providers, Nutrition Professionals, and Family Members

The goal of this *Nutrition Standards of Care* is to promote quality food and nutrition supports for adults with intellectual and/or developmental disabilities (I/DD). These standards and practice guidelines are designed to help personal assistants, direct service staff and others to create and maintain environments that promote all three levels of healthy nutrition:

- Level 1: Adequate Nutrition**
- Level 2: Individualized Nutrition**
- Level 3: Health-Promoting Nutrition**



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### **Background:**

Research shows that a healthy diet would improve the quality and length of most individuals' lives. Poor diet is related to obesity and illnesses such as cardiovascular disease, cancer, diabetes mellitus, and hypertension.

Individuals with primary disabilities often experience "secondary conditions" – additional physical and psychological problems that limit a person's enjoyment of life and participation in activities. Health research conducted with adults who have I/DD shows that diet affects many of their most frequently reported secondary conditions, such as fatigue, weight problems,

and constipation or diarrhea. Proper nutrition can increase these individuals' quality of life by improving existing secondary conditions and preventing additional conditions from developing.

Personal assistants and others responsible for nutrition or planning and preparing meals for adults with I/DD should read the *Standards of Care* and understand how to implement them. Training in safe food handling practices and basic nutrition is necessary. The *Resources* section lists food safety and basic nutrition training materials, including some designed specifically for supported living staff.

### **Minimum Standards of Care for Adults with I/DD:**

- 1. Provide health-promoting food and nutrition supports.**
- 2. Provide information, knowledgeable encouragement, and positive social/instrumental support (assist in grocery shopping, cooking, etc.) to help individuals make good food choices.**
- 3. Support participation in activities that encourage healthy eating and physical activity.**

**Three Levels of Standards:** The goal of these *Standards* is to ensure that individuals with I/DD receive quality food and nutrition that promotes their health and participation in activities. There are

three levels of standards necessary to achieve quality food and nutrition supports. Your role is to help implement the standards at each level, so that each individual:

- Level 1 - Has a diet that is safe and nutritionally adequate.
- Level 2 - Has a diet that addresses his or her special needs.
- Level 3 - Is encouraged to eat recommended portions of healthy foods associated with lower risk for common chronic diseases and conditions.

The **Tree of Good Eating** visually represents the three levels of the **Standards of Care**. The root system is the community and support people who follow the **minimum standards** for quality food and nutrition. The trunk is the **Level 1 Adequate Diet** that is the foundation for quality nutrition. The branches are the **Level 2 Individualized Diet**, the dietary modifications prescribed by a nutrition professional to address the individual's special needs. Finally, the leaves and fruit represent the **Level 3 Health-Promoting Diet** – an investment in a long and healthy life. When basic nutritional needs for routine growth and survival are satisfied, the individual is free to devote energy to other activities and optimal performance.



### Three Levels of Standards of Care

#### Level 1 - Diet is safe and adequate

- Food is of adequate quality and amount
- Variety of fruits, vegetables, and whole grains
- Food is safely stored and prepared
- Menus of 3 meals and snacks per day
- Regular physical activity
- Respects individual food preferences

#### Level 2 - Diet meets individual needs

- The six components of Level One, **plus**:
  - ★ Manages medical conditions
  - ★ Manages secondary conditions
  - ★ Meets other special needs

#### Level 3 - Diet promotes health

- The six components of Level One, **plus**:
  - ★ The three components of Level Two, **plus**:
    - ✓ Abundant whole plant foods
    - ✓ Low cholesterol, saturated and trans fats
    - ✓ Limited simple sugars and salt
    - ✓ More plant proteins (beans, nuts, grains) and fewer and leaner animal proteins (meat)
    - ✓ Multiple vitamin/mineral supplement
    - ✓ Little or no alcohol

**Level 1 – Adequate Diet:** All persons with I/DD must have access to and be encouraged to eat a nutritionally adequate, culturally appropriate, and pleasing diet. Adequacy is defined by the number of servings and portion sizes of foods indicated in the *MyPyramid Food Guidance System* (see

Resources). Variety within and across food groups is important. The number and size of servings are adjusted for an individual's age, sex, and activity level. Emphasis is on food safety and daily consumption of a variety of whole grains, fruits and vegetables.

Personal assistants have a key role in supporting nutritionally adequate choices by:

- Writing, posting, and recording menus that have been developed with as much input from the resident adults with I/DD as possible. Each year, a registered dietitian (RD) or other qualified nutrition professional should review menus to make sure they meet the MyPyramid Food Guidance System, the Dietary Guidelines for Americans, and the Dietary Reference Intake levels for essential vitamins, minerals, and other nutrients. Check with your local hospital, school system food service, or County Public Health Department for a qualified individual to do a free or low-cost menu review.
- Offering three meals and healthful snacks at appropriate times each day.
- Supporting adults with I/DD to engage in moderately-intense physical activity for a total of 30 minutes per day on most days of the week. Sessions may be broken up into 10-minute segments. Diet and exercise go hand in hand. The United States Surgeon General states that, "Regular physical activity can help people with chronic, disabling conditions improve their stamina and muscle strength and can improve psychological well-being and quality of life by increasing the ability to perform activities of daily life."

"Moderately intense physical activity" means that a person: 1) feels some exertion; 2) breathes harder than when resting; yet 3) can talk comfortably. Moderately-intense activities include brisk walking, dancing, swimming, or bicycling on level terrain; or work such as mowing a lawn, cleaning, hauling, lifting, pushing, carpentry, shoveling, or packing large boxes. For greater benefits, a person could increase the number of active days (every day is best), increase the intensity of the activity (go faster), or increase the total amount of time spent being active each day.

**Level 2 – Individualized Diet:** Some individuals need a special diet in order to be adequately nourished. They may have difficulty eating or drinking, have food allergies or dislikes, or have secondary conditions such as diabetes, obesity, or drug side effects, all of which alter a person's nutrient or food needs. A Level 2 therapeutic diet prescribed by a physician or registered dietitian may override other *Standards of Care* recommendations.

For example, physicians or dietitians often prescribe therapeutic diets for individuals with Prader-Willi Syndrome. Most individuals with Prader-Willi Syndrome need support to know when they have eaten enough or when they need to eat more. Without appropriate supports, individuals often overeat and gain an excessive amount of weight. A person with Prader-Willi Syndrome may need high quality, nutrient-dense foods, dietary supplements, and fewer calories in order to balance calories consumed with calories burned.

Individuals with dysphagia, a swallowing disorder, also may have difficulty eating enough of the right foods to stay healthy or maintain an ideal weight. Individuals with dysphagia may also be unable to cough or clear their throats to remove food or liquid that accidentally enters their windpipes. If food or liquid enters the lungs, harmful bacteria may grow and cause aspiration pneumonia. A person with dysphagia needs a special diet of foods and beverages of a manageable consistency, and the support of a multi-disciplinary team of a registered dietitian and speech/or occupational therapist.

A Level 2 diet is part of the person's Personal Supports Plan (PSP) or Individual Plan (IP). A qualified nutrition professional plans and periodically reviews the therapeutic diet menu and provides prior approval for any changes. The nutritionist who plans the therapeutic diet menu should be part of the PSP/IP team discussion of the individual's and staffing resources. It is not appropriate for anyone else to prescribe a diet for an individual or "put" her on a diet, such as a low-carbohydrate or low-fat diet. Individuals on Level 2 diets need to be educated about their needs and included in menu planning.

**Level 3 – Health Promoting Diet:** All Americans can reasonably expect to live a long and healthy life. To live long and well, individuals with I/DD need diets that reduce their risk for chronic diseases. A health promoting diet improves quality of life and is associated with lower rates of secondary conditions, such as overweight and obesity, physical fitness and conditioning problems, depression, fatigue, and heart disease. The Health Promoting Diet:

- Limits simple sugars, salt, saturated fat, trans fat and cholesterol.
- Has moderate total fat, mostly from healthful plant oils.
- Includes ample whole grains, fruits, vegetables, and a good calcium source (dairy, fortified foods, or supplements).
- Limits candy, sodas, desserts, processed meats, and salty snacks (e.g. chips).
- Has low-fat protein mostly from plant sources, and limited amounts of animal protein (i.e. meat).
- For most individuals, includes a multiple vitamin/mineral supplement recommended by his or her health care provider. Unless prescribed by the health care provider, the supplement should provide only 100% of the Dietary Reference Intake appropriate for the individual.
- Includes alcoholic beverages with caution and in moderation (if at all).

### **Practice Guidelines**

Regardless of their living situations, menu planning for adults with I/DD is helpful. A basic menu that has been reviewed for adequacy can serve as a template or model for slightly different, but always nutritionally sound, weekly menus. Menus increase the likelihood that meals will be adequate. They save money because the individual makes fewer shopping trips and only buys items that will be used. Planners can modify weekly or biweekly menus to include sale items or USDA Commodities program foods(see <http://mtdh.ruralinstitute.umt.edu/Publications/Commodities.htm>).

Nutrition education should be a component of the food systems in the homes of adults with I/DD. Caregivers, personal assistants, healthcare providers, and family members can teach basic knowledge of healthy and less healthy foods, safe food preparation, meal planning, and the association between eating well and good health. The resources listed at the end of this document provide basic education on nutrition principles.

Adults with I/DD and their care providers should regularly consult with and obtain guidance from a qualified nutrition professional. The progression of disability and secondary conditions, age, and lifestyle choices can change an individual's nutrient needs. A qualified nutrition professional can review menus, suggest practical tips on improving diets, and screen for nutrition-related disease and secondary conditions.

Caregivers also need appropriate nutrition and food safety training so they can assist in preparing food safely and can recognize unsafe conditions or practices. The goal is to support the individual's greatest possible independence.

## Nutrition Rights for Individuals with Intellectual or Developmental Disabilities

Individuals with intellectual or developmental disabilities (I/DD) have the right to expect:

- Nutritional support from providers who respect their needs.
- A nutritious and adequate diet based on scientific health and nutrition research.
- A culturally-acceptable diet that promotes the individual's health and meets individual needs.
- Safely-prepared and stored food served in a pleasant atmosphere.
- A varied diet of fresh, whole, and minimally-processed foods.
- Choices of foods to include or exclude from an individual's diet.
- Ongoing information about individual dietary needs and appropriate foods to meet those needs.
- Representation in population-based food and nutrition research studies, to ensure that findings generalize to, and are useful for, people with disabilities.
- Fair and respectful treatment from food and nutrition professionals.

These *Standards of Care* are based on the current scientific research on adults with and without disabilities and will be updated regularly. Please note that individuals with I/DD are under-represented in most research studies. Your feedback is important to the nutrition and health of individuals with intellectual or developmental disabilities. We would like to hear from you!

### Resources:

#### General Nutrition Guidelines and Support:

*MyPyramid* (the *Food Guide Pyramid*): Nutrition standards for an adequate diet. Includes a web-based tool to customize the Pyramid for each individual: <http://www.mypyramid.gov/>

*Dietary Guidelines for Americans*: USDA/HHS suggestions for enjoying food and maintaining good health: <http://www.healthierus.gov/dietaryguidelines/>

*American Dietetic Association*: Registered dietitians' professional organization can locate a dietitian in your area: [www.eatright.org](http://www.eatright.org)

*U.S. Department of Agriculture*: Gateway to reliable nutrition information: [www.nutrition.gov](http://www.nutrition.gov)

Cooperative State Research, Education, and Extension Service: Food and nutrition agents provide individualized information on menu and meal planning, food budgeting, and other topics. For local offices, call 202-720-7441 or visit: <http://www.csrees.usda.gov/Extension/>

*Food and Nutrition Information Center*: Information on nutrition, food safety, and U.S. food programs (i.e. food stamps, commodities). Call 301-504-5719 (V) or 301-504-6856 (TTY) or search the index at <http://www.nal.usda.gov/fnic/>

Food Safety Training and Education Alliance: Professional food service web site has safe food handling staff training materials and resources: <http://www.fstea.org>

#### Disability and Health:

*Healthy People 2010*: National health objectives for Americans with and without disabilities: <http://www.healthypeople.gov/>

*Healthy People 2010*, Chapter 6: National health objectives on disability and secondary conditions: <http://www.healthypeople.gov/Document/HTML/Volume1/06Disability.htm>

Montana Disability and Health Program: Nutrition resources for individuals with disabilities:  
<http://mtdh.ruralinstitute.umt.edu/Directory/Nutrition.htm>

U.S. Health and Human Services: Gateway to reliable health information: [www.healthfinder.gov](http://www.healthfinder.gov)

**Physical activity:**

Centers for Disease Control and Prevention: General information and materials on becoming physically active: <http://www.cdc.gov/nccdphp/dnpa/physical/>

National Center for Physical Activity and Disability: Information and guidelines on exercise and activity for individuals with all types of disabilities:  
<http://www.ncpad.org/>

**Write in your local resources here:**

Name

Telephone

Consulting nutritionist or dietitian: \_\_\_\_\_

Public Health Department: \_\_\_\_\_

County Extension Foods/Nutrition Agent: \_\_\_\_\_

Health care provider: \_\_\_\_\_

**For more information, contact:**

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The information provided in this *Standard of Care* was supported by grant #U59/CCU821224-01 from the Centers for Disease Control and Prevention (CDC).

The contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

This *Standard of Care* was prepared by Kathleen Humphries, Meg Traci, Tom Seekins, and the MTDH Advisory Board. The Montana Dietetics Association Executive Board reviewed content. It is available in Braille, large print, and as a text file. A version is also available for individuals with intellectual disabilities.

