Position of the American Dietetic Association: Providing Nutrition Services for People with Developmental Disabilities and Special Health Care Needs

ABSTRACT
It is the position of the American Dietetic Association that nutrition services provided by registered dietitians (RDs) and dietetic technicians, registered (DTRs), are essential components of comprehensive care for all people with developmental disabilities and special health care needs. Nutrition services should be provided throughout life in a manner that is interdisciplinary, family-centered, community-based, and culturally competent. People with developmental disabilities and special health care needs frequently have nutrition concerns, including growth alterations (failure to thrive, obesity, or growth retardation), metabolic disorders, poor feeding skills, medication–nutrient interactions, and sometimes partial or total dependence on enteral or parenteral nutrition. Individuals with special needs are also more likely to develop comorbid conditions such as obesity or endocrine disorders that require nutrition interventions. Poor health habits, limited access to services, and long-term use of multiple medications are considered health risk factors. Health maintenance and avoidance of complications can be promoted by timely and cost-effective nutrition interventions. Public policy for individuals with special needs has evolved over time, resulting in a transition from institutional facilities and programs to community living. The expansion of public access to technology and health information on the Internet challenges RDs and DTRs to provide accurate scientific information for those with developmental disabilities and special health care needs. Nationally credentialed RDs and DTRs are best prepared to provide appropriate nutrition information for wellness and quality of life.


POSITION STATEMENT
It is the position of the American Dietetic Association that nutrition services provided by registered dietitians and dietetic technicians, registered, are essential components of comprehensive care for all people with developmental disabilities and special health care needs.

DEFINING THE POPULATION
Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person’s lifetime (1). It is difficult to determine the prevalence of developmental disabilities in the general population, but in 2008 the Administration on Developmental Disabilities estimated that there were about 4.5 million individuals with developmental disabilities in the United States (2).

Children and youth with special health care needs (CYSHCN) are “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (3). According to the 2005-2006 National Survey of Children with Special Health Care Needs, approximately 10.2 million children ages 0 to 17 years, in the United States (13.9%) have special health care needs (4).

The two terms overlap but also diverge in a significant way. Developmental disabilities encompasses the life span even though the initial onset of the disability manifests itself during childhood. In contrast, CYSHCN is age-based but includes a wider range of conditions: developmental disabilities, chronic diseases, birth-related problems that require extended follow-up (eg, prematurity), congenital defects, and medical issues that may be resolved through medical/surgical intervention by the time a child reaches adulthood.

The National Organization on Disability (http://www.nod.org) emphasizes that not all individuals with disabilities use visible, assistive devices, giving rise to the term invisible or hidden disabilities. These disabilities can include hearing, cognitive, or psychiatric impairments, or chronic, disabling diseases that may not be physically apparent (5).

PUBLIC POLICY
There is a long history, beginning in the early 20th century, of federal involvement in policy, programs, and funding for individuals with disabilities and special health care needs. Several key pieces of public policy are of particular interest to registered dietitians (RDs) and dietetic technicians, registered (DTRs).

Title V of the Social Security Act, initially established in 1935, provides funding for state maternal and child health services, including services for CYSHCN (6). Title XIX of the Social Security Act funds Medicaid, an entitlement program that finances medical services for low-income individuals and families. Eligibility criteria, covered services and mechanisms for
reimbursement and service delivery vary widely because states design and administer the Medicaid program under broad federal guidelines (7). For some children from families with low income, Medicaid may pay for services such as special dietary supplements, eating devices, and nutritional consultation if they are deemed medically necessary. The Early Periodic Screening, Diagnosis, and Treatment Program is a required component of Medicaid and is designed to improve the health of low-income children, including children with disabilities, by financing appropriate and necessary pediatric services (8). The State Children’s Health Insurance Program (SCHIP) (Title XXI of the Social Security Act) was created in 1997 to ensure children in families who had too much income to qualify for Medicaid but too little to afford private insurance (9).

Project Head Start, created in 1965 to promote school readiness among preschool children from low-income families by enhancing their social and cognitive development through the provision of educational, health, nutrition, social, and other services, was mandated to serve children with disabilities in 1972. At least 10% of its national enrollment was set aside for these children. Early Head Start was established in 1995 to serve children from birth to 3 years of age. The Head Start Act was reauthorized in 2007 (10,11).

The Individuals with Disabilities Education Act requires schools to make a free, appropriate public education in the least restrictive environment appropriate to individual needs available to all eligible children with disabilities. It also promotes education in early intervention and preschool programs, transition programs to help prepare youths with disabilities to enter the adult world, and requires schools to develop Individualized Education Programs for each child outlining the specific special education and related services needed by the individual student with disabilities (including feeding support or nutrition goals if appropriate) (12-14).

The Child Health Act of 2000 amended the Public Health Service Act with respect to children’s health and created the National Center for Birth Defects and Developmental Disabilities (Centers for Disease Control and Prevention) and the Healthy Start Initiative. Among the 34 titles in this act are sections relating to autism, fragile X syndrome, juvenile arthritis, asthma, diabetes, epilepsy, autoimmune diseases, muscular dystrophy research, and childhood obesity programs (15).

University Centers for Excellence in Developmental Disabilities evolved from the Developmental Disabilities Assistance and Bill of Rights Act (16). Located in a university setting, these centers are in every state and territory. Many have RDs on their interprofessional staff.

In response to Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990, which prohibits discrimination based on disability (17), the US Department of Agriculture included specific provisions in its National School Lunch Program regulations for children and youth with disabilities and special health needs (18):

- “Schools must make substitutions in lunches and afterschool snacks for students who are considered to have a disability... and whose disability restricts their diet.”
- “Schools may also make substitutions for students who do not have a disability but who cannot consume the regular lunch or afterschool snack because of medical or other special dietary needs.”

In 2004, the Child Nutrition and WIC Reauthorization Act of 2004 included Section 204, which mandated the establishment of local school wellness policies by the first day of the school year beginning after June 30, 2006 (19). A major focus of school wellness policies is “preventing childhood obesity and combating problems associated with poor nutrition and physical inactivity” (19).

In 1999, the US Supreme Court ruled in Olmstead vs LC that unjustifiable institutionalization of a person with a disability who, with proper support, can live in the community is discrimination under the Americans with Disabilities Act (20). In response to the Olmstead decision, President Bush established the New Freedom Initiative in 2001 to remove barriers to community living for people with disabilities and long-term illnesses (21).

The July 22, 2004, Individuals with Disabilities in Emergency Preparedness Executive Order created the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (22). This may be an area for RDs to become involved to ensure that the nutrition and hydration needs of CYSHCN and individuals with disabilities, especially those with oral-motor and feeding problems, can be adequately addressed in an emergency situation.

CHARACTERISTICS OF THE POPULATION, REVIEW OF SELECTED CONDITIONS, AND NUTRITION RISK FACTORS

Characteristics

The altered physical growth rate and body composition often seen in persons with developmental disabilities may result from prenatal, perinatal, or postnatal causes (23,24). Prenatal causes vary and include chromosomal differences, such as Down syndrome, or exposure to a virus like cytomegalovirus, or to drugs or alcohol. Perinatal and postnatal conditions such as cerebral palsy, bronchopulmonary dysplasia, congenital heart disease, or traumatic injury may result in permanent growth stunting because of associated increased energy needs, feeding difficulties, and medical conditions (25,26).

Life expectancy for individuals with developmental disabilities has increased to the extent that younger adults with developmental disabilities are expected to have little disparity in relation to longevity. For older adults disparities may continue to exist. The shift to home- and community-based care for individuals with developmental disabilities has changed how services, including nutrition services, are delivered (2).

People with developmental disabilities have an increased risk for chronic diseases such as heart disease, obesity, seizures, hearing and vision problems, low bone mineral density, and poor conditioning and fitness (25,27). The severity of the nutritional problems depends on multiple factors unique to each individual (age, level of functioning, severity of disability, general state of health), as well as environmental, educational, training, work, and social conditions. As the population ages, comorbidities are being studied, such as the link...
<table>
<thead>
<tr>
<th>Syndrome or developmental disability</th>
<th>Nutrition diagnostic terms</th>
<th>Indicators of this nutrition diagnosis</th>
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<tbody>
<tr>
<td><strong>Autism spectrum disorders (ASD)</strong></td>
<td>Inadequate energy intake</td>
<td>Limited or restricted food choices</td>
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<td>Characterized by delayed speech and</td>
<td>Excessive energy intake</td>
<td>High intake of food (kcal) due to food obsessions or use of food for behavioral interventions</td>
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<td>language development, ritualistic or</td>
<td>Food-medication</td>
<td>Potential interactions between food and a variety of medications used for individuals with ASD</td>
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<td>repetitive behaviors, and impairments</td>
<td>interactions</td>
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<td>in social interactions.</td>
<td>Underweight</td>
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<td>Inadequate energy intake</td>
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<td></td>
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<td>Body mass index (BMI) &lt;5th percentile for children 2-19 y</td>
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<td>Refusal to eat</td>
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<td>Restricted or limited food choices that result in low energy intake</td>
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<td><strong>Overweight</strong></td>
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<td>BMI &gt;85th percentile for children 2-19 y</td>
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<td>Excessive energy intake</td>
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<td>Infrequent, low duration, and/or low intensity physical activity</td>
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<td>Large amounts of sedentary activities</td>
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<td>Limited food choices that result in excessive energy intake</td>
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<td><strong>Harmful beliefs/attitudes</strong></td>
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<td>Eating behavior serves a purpose other than nourishment</td>
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<tr>
<td>about food</td>
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<td>Pica</td>
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<td>Food fetish</td>
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<td><strong>Undesirable food choices</strong></td>
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<td>Intake that reflects an imbalance of nutrients/food groups</td>
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<td>Avoidance of foods/food groups</td>
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<td>Complementary and alternative medicine treatments, often nutrition-based (vitamin B-6 supplements, gluten-free casein-free diet) may place child at risk for nutrient deficiencies</td>
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<td>Intake inconsistent with Dietary Reference Intakes, US Dietary Guidelines, MyPyramid, or other methods of measuring diet quality</td>
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<td>Inability, unwillingness, or disinterest in selecting food consistent with the guidelines</td>
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<td>Condition associated with diagnosis, ASD–food selectivity, rigid eating patterns</td>
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<td><strong>Increased energy expenditure</strong></td>
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<td>Unintentional weight loss</td>
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<td>Evidence of need for accelerated or catch-up growth or weight gain; absence of normal growth</td>
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<td><strong>Inadequate energy intake</strong></td>
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<td>Condition associated with a diagnosis (eg, cerebral palsy)</td>
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<td>Failure to gain or maintain appropriate weight</td>
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<td>Insufficient energy intake from diet compared to needs</td>
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<td><strong>Excessive energy intake</strong></td>
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<td>Inability to independently consume foods/fluids</td>
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<td>Increased body adiposity</td>
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<td>Weight gain greater than expected</td>
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<td>Enteral nutrition more than measured/estimated energy expenditure</td>
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<td><strong>Swallowing difficulty</strong></td>
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<td>Abnormal swallow study</td>
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<td>Prolonged feeding time</td>
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<td>Coughing, choking, prolonged chewing, pouching of food, regurgitation, facial expression changes during eating</td>
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<td>Decreased food intake</td>
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<td>Avoidance of food</td>
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<td>Mealtime resistance</td>
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<td><strong>Altered gastrointestinal (GI) function</strong></td>
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<td>Condition associated with diagnosis: Internal muscle tone in cerebral palsy can be affected as well as more visible external muscle tone</td>
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<td><strong>Food-medication interactions</strong></td>
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<td>Seizure medications: food and medication interactions</td>
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<td><strong>Underweight</strong></td>
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<td>Inadequate energy intake</td>
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<td>BMI &lt;5th percentile for children 2-19 years</td>
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<td>Decreased muscle mass, muscle wasting</td>
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<td>Inadequate intake of food compared to estimated or measured needs</td>
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<td>History of physical disability or malnutrition</td>
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<td><strong>Overweight</strong></td>
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<td>BMI &gt;85th percentile for children 2-19 years</td>
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<td>Excessive energy intake</td>
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<td>Large amounts of sedentary activities</td>
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(continued)

Figure 1. Frequently reported nutrition concerns using standardized language for the Nutrition Care Process for selected syndromes and developmental disabilities. Adapted from references 14, 34, and 44.
<table>
<thead>
<tr>
<th>Syndrome or developmental disability</th>
<th>Nutrition diagnostic terms</th>
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</thead>
</table>
| **Cystic fibrosis**                 | Increased energy expenditure | Unintentional weight loss  
Evidence of need for accelerated or catch-up growth or weight gain; absence of normal growth  
Condition associated with a diagnosis (eg, cystic fibrosis) |
|                                     | Altered gastrointestinal function | Abnormal digestive enzyme and fecal fat studies  
Malabsorption  
Steatorrhea |
|                                     | Impaired nutrient utilization | Abnormal digestive enzyme and fecal fat studies  
Growth stunting or failure  
Evidence of vitamin and/or mineral deficiency  
Steatorrhea  
Condition associated with diagnosis: cystic fibrosis |
| **Down syndrome**                   | Excessive energy intake | Increased body adiposity  
Energy intake higher than estimated need  
Reduced energy needs related to short stature, low muscle tone |
|                                     | Breastfeeding difficulty | Poor sucking ability as an infant (due to low tone)  
Poor weight gain |
|                                     | Altered GI function | Constipation (related to low muscle tone, low activity, and/or low fiber intake)  
Colic disease (higher incidence in Down syndrome) |
| **Prader-Willi syndrome (PWS)**    | Excessive energy intake | Increased body adiposity  
Energy intake higher than estimated need  
Condition associated with diagnosis (eg, hyperphagia and PWS)  
Reduced energy needs related to short stature, low muscle tone |
|                                     | Breastfeeding difficulty | Poor sucking ability as an infant (due to low tone)  
Poor weight gain |
|                                     | Harmful beliefs/attitudes about food | Eating behavior serves a purpose other than nourishment  
Pica  
Food obsession  
Undesirable food choices |
|                                     | Excessive energy intake | Increased body adiposity  
Energy intake higher than estimated need  
Condition associated with diagnosis (eg, hyperphagia and PWS)  
Reduced energy needs related to short stature, low muscle tone |
|                                     | Swallowing difficulty | Abnormal swallow study  
Noisy wet upper airway sounds  
Condition associated with diagnosis of Arnold Chiari malformation of the brain  
Constipation  
Altered gastrointestinal function |
|                                     | Altered gastrointestinal function | Condition associated with diagnosis: neurogenic bowel |

Figure 1. Continued
between Down syndrome and Alzheimer's disease (28,29). Nutrition intervention may provide preventive or therapeutic nutrition strategies.

Review of Selected Conditions
See Figure 1 for selected syndromes and developmental disabilities and frequently reported nutrition concerns.

Facial Cleft Conditions. Orofacial or craniofacial clefts can present as cleft of lip, or hard or soft palate. Reported problems include feeding difficulties and obtaining adequate nutrition to support possible oral or dental surgeries (30).

Genetic or Inherited Metabolic Disorders. Expanded newborn screening for inherited metabolic disorders is now performed in most states and the number of new patients is expanding rapidly (31). A database listing current screening status for these disorders in each of the 50 states is available at http://genes-r-us.uthscsa.edu/.

Regional differences in incidences of these disorders exist and regional collaborative groups have organized to provide services and research initiatives. Although all are rare, genetic disorders more commonly seen include phenylketonuria, which can cause severe to profound mental retardation; maple syrup urine disease, where effects of uncontrolled levels of branched chain amino acids can cause coma and death; and medium chain fatty acid oxidation disorders that can be fatal without early detection/treatment. Other disorders include urea cycle disorders, amino acidopathies, carbohydrate metabolism disorders, or transporter defects. Adults and older children, born before screenings were available, may have brain damage or other organ system symptoms from damage before diagnosis. Children born after screening began have the potential of earlier diagnosis and treatment, preventing many of the severe effects of these metabolic disorders. However, these children require frequent monitoring and special diets into adulthood, including metabolic formulas and severe restriction of food or nutrient groups, putting them at risk for other nutrition concerns. Patients should be monitored by metabolic specialists at clinics in each state. Unfortunately, if individuals with metabolic disorders do not maintain good nutrition control or if other illnesses interfere, the symptoms mentioned above may occur (32).

Nutrition Risk Factors

Weight Status. Overweight and obesity in persons with developmental disabilities can place an extra burden (literally) on caregivers when that...
person is dependent on physical assistance for activities of daily living. Being overweight can become a secondary disability for an individual who already has movement difficulties or limitations. Overweight may have negative social consequences, but more significantly, it contributes to the development of chronic diseases such as diabetes, hypertension, and heart disease (27).

Studies have found a higher incidence of overweight and obesity in persons with developmental disabilities and with Down syndrome than in the general population (33). This prevalence of obesity is a major health problem that needs further attention from researchers and RDs and DTRs working with this population.

Overweight and obesity, as well as short stature, limited mobility, and inappropriate eating practices such as pica, are also seen in people with other syndromes such as Prader-Willi or Lawrence Moon-Bidel syndrome. With the use of growth hormone, individuals with Prader-Willi syndrome have shown improved linear growth and final height, as well as improvements in body composition, with few side effects (34). Evidence-based approaches such as those included in the American Dietetic Association (ADA) Evidence Library (www.adaevidencelibrary.com) should be used. These include reduction in energy intake for weight maintenance, daily aerobic exercise, food monitoring procedures, and an interdisciplinary approach for behavior modification.

Underweight can be a significant risk factor for people with Rett syndrome, cerebral palsy, oral motor problems, or other developmental disabilities. People with mobility problems who are significantly below a desirable weight are at risk for decubitus ulcers, specific nutrient deficiencies due to inadequate intake, and further weight loss if ill and unable to eat (35).

**Drug Use and Interactions.** The long-term use of medications can result in medication and nutrient interactions. Abnormalities in vitamin D, calcium and bone status, constipation, and gum hyperplasia have been associated with the long-term use of anticonvulsants in persons with developmental disabilities who have limited mobility (36). Many adolescents and adults with developmental disabilities take multiple medications for extended periods of time and are at risk for complications caused by interactions. In addition, medication may have a longer half-life because of decreased lean body mass. Use of medications such as antibiotics for recurrent urinary or respiratory infection may produce gastrointestinal symptoms. Psychotropic drugs may affect appetite by increasing it or decreasing it, subsequently affecting weight. Constipation, as a side effect of long-term use of psychotropics, anticonvulsants, or other medications, may result in fecal impactions, increased use of stool softeners, or changes in nutrient absorption.

Attention deficit hyperactivity disorder (ADHD) is commonly treated with stimulant medications such as methylphenidate. Studies show that these medications may depress appetite in children, resulting in a slower rate of weight gain and growth. This should be monitored by a health care team and RD. Effects on growth may be reduced by taking “vacations” from the medication during summer or school breaks. There is also some indication that catch-up growth may occur during puberty (37,38). Tricyclic antidepressants are used to treat depression and as a treatment for ADHD for some young adults and children over age 6 years. Nutrition-related side effects include increased appetite, nausea and vomiting, constipation, and diarrhea (37). There is some recent evidence of nutritional and dietary influences on behavior and learning in children with ADHD, with the strongest support to date reported for n-3 fatty acids and behavioral reactions to food components (such as food coloring) (38).

**ORAL MOTOR AND FEEDING ISSUES**

Oral motor problems, dysphagia, food allergies, and food aversions complicate the process of implementing medical nutrition therapy (26). Many children and adults depend on caregivers to provide the appropriate amount of food and fluid to achieve desired weight and meet their nutrient needs. Regular periodic weighing (weekly or monthly) is important to evaluate if energy intake is adequate. An RD or DTR should review and monitor weights, and may need to assist caregivers in finding an appropriate place and the appropriate frequency of weighing. Signs of impaired swallowing function (eg, coughing, choking, wet breathing, changes in respiratory pattern) or other eating difficulties should trigger a referral for further evaluation and intervention (26,39).

Tube feedings may be recommended in some patients with failure to thrive, aspiration pneumonia, dysphagia, or the inability to ingest adequate energy orally to promote growth or maintain nutritional status. Volume toleration is difficult for some people. Whether receiving a commercial or homemade blended formula, people of all ages with tube feedings require ongoing monitoring and evaluation by an RD or DTR. Monitoring is especially critical in a group home or community setting in which health care providers may change frequently and not be adequately trained (40,41).

**UNIQUE ISSUES FOR NUTRITION ASSESSMENT**

Three frequently encountered issues in nutrition assessment are special measuring techniques/equipment, specialized growth charts, and determining energy needs. Instructions on special measuring considerations and equipment, as well as special growth charts, are available from the Health Resources and Services Administration at http://depts.washington.edu/growth/. Special growth charts exist for some syndromes and conditions; however, their use in nutrition assessment is controversial. Most were developed using small populations, do not include all growth parameters, and some use old or retrospective data. Growth charts commonly used are for Down syndrome, cerebral palsy, and Prader-Willi syndrome, although comparison with standardized growth charts and clinical judgment are still appropriate.

Assessing energy requirements is challenging because requirements differ depending on the diagnosis, the severity of the disability, mobility status, number of medications and side effects, and feeding problems. Decreased metabolic needs of individuals with Prader-Willi syndrome have already been mentioned. Many studies have been conducted to assess en-
nergy expenditure for people with cerebral palsy. Energy requirements may be increased or decreased depending on the presence or absence of athetoid movements (42,43).

There are many other assessment issues unique to this population beyond the scope of a position paper. Information throughout this paper points to programs that will help RDs and DTRs locate current best practices and develop needed skills. As with implementation in any setting, practice and peer discussion will help use the Nutrition Care Process and standardized language to reflect the nutrition care needs of this population (44).

**ADVANCES IN GENETICS/GENOMICS AND NEONATOLOGY THAT AFFECT DEVELOPMENTAL DISABILITIES**

**Genetics/Genomics**
The field of genetics has evolved rapidly since the completion of the Genome Project in 2003. A genetics science primer is available at [www.ncbi.nlm.nih.gov/About/primer/genetics_cell.html](http://www.ncbi.nlm.nih.gov/About/primer/genetics_cell.html). DeBusk (45) reviews genomics and the general influence of genome findings on human health care, defining genomics as “the new genetics—the study of the interaction of multiple genes on function...and protein-protein...and gene environment interaction.” The Human Genome Project set out to determine each of the DNA bases and the sequence of the bases within human DNA, which are translated into useful products, to develop fast sequencing technology and the databanks to store the information and train scientists. Exploration as to how genes function and interrelate to the environment followed, to serve as the foundation for new endeavors in technology, diagnostics, preventative medicine and nutrition, and designer pharmacology. Detailed mutation analysis and micro arrays (“gene chip” technology) are now available. Proteomics is the study of what proteins are expressed by the genes and their function(s) in the organism (45). These advances have resulted in rapid diagnosis of genetic abnormalities including gene mutations, altered biochemical pathways, and mitochondrial disorders. Timely diagnoses of disorders will lead to rapid referrals to clinicians for care and early intervention services. This information is available for research about genetic disorders, treatment strategies, and the variability of disease course. RDs and DTRs will be involved in many of these endeavors.

**Neonatology Medicine/Population**
Neonatology is a specialty area of medicine and nutrition (46). The high rate of premature births and increased survival of low birth weight infants will result in increased numbers of babies with emergent care needs as critically ill newborns as well as some incidence of developmental delays and disabilities. The March of Dimes reports that the rate of preterm births in the United States rose to 12.7% in 2007, an increase of 36% since the early 1980s. They report that preterm birth is a leading cause of death in the first months of life. Preterm infants who survive have an increased risk of serious health problems such as breathing problems, feeding difficulties, temperature instability, jaundice, delayed brain development, and an increased risk of cerebral palsy and mental retardation (47). Many premature babies will be seen in specialty clinics for pulmonary and gastrointestinal conditions as well as premature follow-up clinics. Long-term medical follow-up and feeding therapy will be needed in all levels of care.

**CONSUMER AND HEALTH CARE TRENDS**

**Health Insurance and Payment for Health Services**
The US Census Bureau reports that approximately 45.7 million Americans were without health insurance for all of calendar year 2007. A report by Families USA found that 87.6 million people under the age of 65 (33.1% or one in three) were without health insurance for all or part of 2007-2008. Every race and ethnic group is represented among the uninsured (48).

Medicaid and SCHIP provide health coverage to more than 30 million low-income children, with about three out of four eligible children participating. Studies show that children, including those with special health care needs, enrolled in SCHIP have improved access to care as measured by reductions in unmet health care needs, increased use of preventive care, and an increased likelihood to have a regular source of care (49).

In a study by the University of Florida Institute for Child Health Policy, CYSHCN were estimated to be <10% of Medicaid and SCHIP enrollees but accounted for approximately 38% to 44% of total health care expenditures. Services such as care coordination should be considered because there is some evidence that these programs can help promote high quality health care while reducing health care expenditures (50). As Congress addresses the issues of health care costs, health care finance reform and health care coverage for large numbers of uninsured Americans over the next several years, it will be important to make certain that those individuals with complex, chronic, and sometimes costly health care needs are also represented.

**Medical Home**
A medical home is a central place where individuals receive primary health care but it involves more than a place, it includes the process and scope of care provided and the team of people who deliver and coordinate that care. With a medical home, patients and families can expect that physicians and staff will know and remember them; will respect their ideas, customs, and beliefs; and help them coordinate care and information among multiple professionals and services. RDs and DTRs working with CYSHCN, who are not affiliated with the family’s medical home provider, should clarify with the family that the child does, indeed, have a medical home, and should obtain necessary permissions to begin a dialogue with that medical home to ensure that nutrition services are part of coordinated and effective care for the child. Information about the medical home concept can be found at the National Center of Medical Home Initiatives for Children with Special Needs (http://www.medicalhomeinfo.org/). ADA has recently issued a strategic plan on involvement of RDs and DTRs in patient-centered medical homes (see Figure 2).

**Electronic Records**
Health information technology and electronic health records are increasingly seen as critical to quality, cost-effective health care. Health care
Complementary and Alternative Medicine (CAM)

CAM is “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine” (52). Information about CAM can be obtained from the National Center for Complementary and Alternative Medicine (www.nccam.nih.gov).

Many CAM therapies include nutrient or herbal supplements or special diets. The rate of CAM use for CYSHCN is estimated to be 30% to 70%. Some families adopt CAM therapies, not out of dissatisfaction with conventional medicine, but because these alternatives are more consistent with their values, beliefs, and philosophical orientation toward health and life. Others seek CAM therapies out of a fear of adverse drug effects, dissatisfaction with conventional medicine, and/or the need for more personal attention. In many instances, word-of-mouth that a particular treatment is effective is a compelling reason to try a CAM therapy. Health care providers, including RDs and DTRs, who counsel individuals with developmental disabilities and CYSHCN, have a responsibility to provide information to patients and families about relevant, safe, effective, and age-appropriate services and therapies regardless of whether they are considered mainstream, conventional, or CAM. The American Academy of Pediatrics suggests that practitioners ask directly and nonjudgmentally about the use of these therapies; maintain open and ongoing communication centered on the patient’s well-being, but respectful of an individual’s or family’s perspectives, values, and cultural beliefs; monitor patient responses to treatment and establish measurable outcomes for evaluation; and maintain up-to-date knowledge of popular CAM and evidence-based resources (53).

WELLNESS, PREVENTION OF DISEASE, AND TRANSITION TO ADULT HEALTH CARE SERVICES

Needs for wellness and disease prevention for individuals with developmental disabilities and CYSHCN are similar to those for the general population (eg, physical activity, nutrition, access to health care, clinical preventive services, oral care, mental health, and family care giving). Healthy People 2020, a comprehensive set of national public health objectives, which builds upon previous Healthy People goals, is being developed for release in 2010. The Healthy People Advisory Committee has released an executive summary outlining the vision and goals for Healthy People 2020, which include (54):

1. Eliminate preventable disease, disability, injury, and premature death.
2. Achieve health equity and eliminate health disparities.
3. Create social and physical environments that promote good health for all.
4. Promote healthy development and healthy behaviors at every stage of life.

The Advisory Committee stated that the Healthy People 2020 framework should employ a “life course approach” to health promotion because exposures early in life can be linked to outcomes later in life (54). A life course approach to disabilities and special health care needs considers a “complex interplay of biological, psychological, and social protective and risk factors that contribute to health outcomes across an individual’s life span” (55). An example of this approach can be seen in a review by Tyler and coworkers (56) of early environmental exposures that can result in intellectual and developmental disabilities.

One important aspect of health care for individuals with developmental disabilities or special health care needs across their life course is an appropriate and effective transition in health services from pediatric systems of care to adult service systems. This transition is one of the outcomes for measuring success of community-based systems of care for youth with special health care needs according to the Maternal and Child Health Bureau. Adult health care options should be available within the community and provided within a developmentally appropriate setting. Services for youth should prepare them to take charge of their own health and to lead as productive a life as they choose (57). However, in the 2005-2006 National Survey of Children with Special Health Care Needs, only 41% of youth with special health care needs met the Maternal and Child Health Bureau core performance outcome for transitions (58).

The increases in life expectancy and improvements in health and functional outcomes for youth with special health needs and disabilities have presented new challenges to the health and social service systems. Between the ages of 16 and 21 years, individuals often become ineligible for the services that they have used and depended on throughout their early life. The transition in health care can be particularly challenging because the adult health care system tends to be more fragmented and rarely includes multidisciplinary teams that are central to the care of challenging and complex disabilities such as spina bifida or cerebral palsy (59).

One approach to address some of these issues has been the establishment of “transition” clinics that include consultation with both the child and adult health care providers. Another key concern is maintaining health insurance coverage during the transition from pediatric to adult services (59). For RDs and DTRs, a major barrier to providing services to older adolescents and adults with disabilities is the lack of payment for services. Transition issues are being examined by groups such as the American Academy of Pediatrics (www.aap.org) and state and federal maternal and child health programs.

COMPONENTS OF COMPREHENSIVE NUTRITION SERVICES

Nutrition Services

An RD’s or DTR’s role as an effective member of the health care team is to
assess the clinical, biochemical, and anthropometric measurements; dietary concerns; feeding skills; and to understand the environmental, social, economic, and educational factors that will affect the intervention plan developed for the client (44). As an interdisciplinary team member for clients with developmental disabilities or special health care needs, this may include training other disciplines, clients, families, and/or caregivers in food selection and preparation as a part of the intervention plan (60). ADA and its state affiliates often hold continuing education programs to expand the knowledge in areas specific to or related to this population. Dietetic practice groups, such as those for behavioral health, pediatrics, and geriatrics, to mention only a few, also provide resources in various forms.

Roles and Responsibilities
Services provided by an RD or DTR are essential to the health of clients with special needs. Practitioners should develop or adopt effective and individualized nutrition screening, assessment, and monitoring tools. A nutrition assessment should target some of the variations found in physical growth. Cognitive assessment provides understanding of the client’s functional ability and leads to development of appropriate treatment plans. Lower level literacy programs may be appropriate for some clients (60). It is important to be sensitive to chronological age as well as cognitive function; materials designed for children are usually not appropriate for adolescents or adults. One study examining the factors influencing nutrition education for persons with low literacy proficiency suggested that effective nutrition interventions must build on patients’ social networks, appear in a visually based and interactive format, and be culturally appropriate (61). Nutrition services may need to include families and caregivers in addition to clients (62). Communication skills should also be considered. Some clients may exhibit little expressive language or poor speech articulation. Practitioners should adopt appropriate communication methods.

Evaluation of feeding skills is an important component of the assessment and intervention program. The goal of the feeding program may be to achieve independence without placing the client at nutrition risk. Other interdisciplinary team members are involved in determining the treatment plan for the client, which may include self-help feeding equipment or safe food textures and consistencies. Often an RD or DTR is the team member who reinforces the plan, and should be the one who determines the food choices appropriate for the client (26,63).

Education of RDs and DTRs for this Population
RDs and DTRs in this area need to seek specialty training in clinical settings, at educational conferences, and through appropriate dietetic practice and subspecialty groups. It is also highly desirable to have additional training in the grant writing process and research/institutional review boards to participate in research and to help fund salaries as needed. There are also formal training programs provided through various federal programs as training grants.

The Administration on Developmental Disabilities is a federal agency that funds grantees to partner with state governments, local communities, and private agencies to assist people with developmental disabilities to reach their potential through increased independence, productivity, and integration within the community. One component that affects education is the national network of University Centers for Excellence in Developmental Disabilities (UCEDD). Discretionary grant funding is used for interdisciplinary training, research, information dissemination, and community service (http://www.audc.org/template/page.cfm?id=24). The Maternal and Child Health Bureau funds Leadership Education in Neurodevelopmental Disorders (LEND) programs, interdisciplinary leadership training programs based in universities, in many states. The purpose of the LEND training program is to improve the health of infants, children, and adolescents with disabilities by preparing trainees from diverse professional disciplines to assume leadership roles in their respective fields and by ensuring high levels of interdisciplinary clinical competence (http://www.audc.org/template/page.cfm?id=6).

The Association of University Centers on Disabilities (www.aucd.org) includes UCEDD, LEND, and Intellectual and Developmental Disability Research Centers programs. The goal of this nationwide network is to bring validated, best-practice disability initiatives into community practice in each state. These programs train individuals for leadership positions; train direct care workers for community service; work to ensure that systems are designed so that people with disabilities have access to the services and the supports they need; conduct research; provide technical assistance to agencies and the community; and disseminate information to individuals with disabilities, families, public and private agencies, and policymakers. RDs and DTRs should locate the UCEDD, LEND, or Association of University Centers on Disabilities programs closest to their community and investigate available services to learn more about providing nutrition services for this population.

Protocols and Standards of Care
ADA has not yet developed evidence-based practice guidelines for nutrition services specific to the population with developmental disabilities and special health care needs. However, evidence-based practice guidelines are available for many of the diseases and conditions that occur in these individuals, including chronic obstructive pulmonary disease, hypertension, diabetes mellitus type 1 and 2, pediatric weight management, and adult weight management (www.adaevidencelibrary.com). A long-term goal to develop protocols or guidelines for individuals with developmental disabilities would facilitate the goal of increasing reimbursement for services (64).

ADA’s Standards of Practice and Standards of Professional Performance for Registered Dietitians (Generalist, Specialty, and Advanced) in Behavioral Health Care, which includes standards for RDs and DTRs working with people with developmental disabilities or special health care needs, were first published in 2006 (60). They are currently under review to update specific areas of practice within behavioral health.
Recommendations

To provide comprehensive nutrition services for infants, children, adolescents, and adults with developmental disabilities and special health care needs, ADA recommends that RDs and DTRs engage in the following:

- Develop and implement content or field experience programs in undergraduate and graduate programs that address the nutrition concerns of persons with developmental disabilities and special health care needs.
- Provide specialized interdisciplinary nutrition training for practicing RDs and DTRs to address the health concerns of persons with developmental disabilities and special health care needs.
- Provide opportunities for all health and human service providers to increase their level of nutrition knowledge related to persons with developmental disabilities and special health care needs.
- Promote and provide timely and cost-effective nutrition services, including ongoing nutrition monitoring, as an essential component of health care programs for persons with developmental disabilities and special health care needs throughout the life span.
- Support programs that promote health and wellness throughout the life span for persons with developmental disabilities and special health care needs.
- Develop and implement evidence-based medical nutrition therapy protocols that address the unique needs of persons with developmental disabilities and special health care needs.
- Encourage participation of nationally credentialed RDs and DTRs on primary and specialty care teams and in vocation, education, and residential programs that serve persons with developmental disabilities and special health care needs throughout the life span.
- Support inclusion of nationally credentialed RDs and DTRs experienced in the unique nutrition needs of persons with developmental disabilities and special health care needs in agencies developing policy in the areas of education, vocation, and health services at the federal and state levels.
- Collaborate with health care providers to ensure there are policies in place to promote family-centered, interdisciplinary, coordinated, community-based, and culturally competent services for persons with developmental disabilities and special health care needs.
- Work to obtain reimbursement for medical nutrition therapy as part of comprehensive health care for persons with developmental disabilities and special health care needs.
- Advocate for nutrition services to be included in service provisions for persons with developmental disabilities and special health care needs throughout the life span.
- Support and participate in medical/nutrition research and publishing in primary and secondary areas of disease risks for persons with developmental disabilities and special health care needs, including institutional review board and grant writing training.

References

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