

# Special Health Matters

## Nutrition-related Problems

### ♥ Who is at risk for nutrition-related Health Problems?

Children and youth with special health care needs are at risk for nutrition-related health problems. This population is defined as “those (children/youth) who have or at increased risk for a chronic physical, developmental, behavioral, or emotional condition who require health and related services of a type or amount beyond that required by children generally.”

Approximately 7-18% of children and youth ages birth to 18 years in the United States have a chronic physical, behavioral, developmental or emotional condition causing limitations in activities, and/or requiring special care.

The etiology of developmental disabilities and special health care needs is complex. Children and youth with special health care needs may have physical impairments, developmental delays or chronic medical conditions that are caused by are associated with the following factors;

- **Chromosome anomalies, genetic conditions**
- **Congenital infections**
- **Inborn errors of metabolism**
- **Prematurity**
- **Neurologic insults**
- **Neural tube defects**
- **Trauma**
- **Maternal substance abuse**
- **Environmental toxins**

### ♥ What is the significance of nutrition-related problems in children with special health care needs?

It is estimated that up to 40-50% of children and adolescents with special health care needs have nutrition-related risk factors or health problems that require the attention of a registered dietitian, nutritionist, or health care professional. Nutrition risk factors may be physical, biochemical, psychological or environmental in nature. Physical conditions such as cleft lip or palate or a disease process such as cystic fibrosis may limit an individual's ability to feed, digest, or absorb food. Drug-nutrient interactions may alter digestion, absorption or the bioavailability of nutrients in the diet. Psychological factors play a role in an individual's ability to accept and cope with a disability or treatment plan. For example, depression may alter an individual's appetite and motivation to follow a specified diet plan. Environmental factors such as family and social support, finances and reinforcements for following certain dietary regimens. One or more of these factors may put a child or adolescent with special health care needs at risk for nutrition problems. Common nutrition problems for the child or youth with special care needs may include the following:

- **Altered energy and nutrient needs**
- **Delayed or stunted linear growth**
- **Underweight**
- **Overweight or obesity**
- **Feeding delays or oral-motor dysfunction**
- **Elimination (bowel) problems**
- **Drug-nutrient interactions**
- **Appetite disturbances**
- **Unusual food habits**
- **Dental and gum disease**

### ♥ How can intervention help?

Nutrition services for a child or youth with special health care needs may require more specialized services to address complex nutrition issues and may involve an interdisciplinary team. The team approach allows for individuals from different disciplines to address the multifaceted problems that may impact nutrition and feeding. The child and caregiver(s) should be key members of the team in the identification of problems and setting priorities to be addressed in the treatment plan. Through the team approach a comprehensive plan is developed to address all factors that may impact growth, development, and general health. The goal of the treatment plan is to provide optimal nutrition to support growth, development and level of functioning.

Examples of the problems that may impact feeding and the respective team members to address these needs are outlined below:

- **Medical issues—physicians, nurses**
- **Neuro-motor problems—physical therapists, occupational therapists, speech pathologists**
- **Behavior problems—psychologists**
- **Dental and oral health problems—dentists**
- **Financial issues and—social workers**
- **Community resources—local health education and information center**
- **Quality and quantity of diet, growth—dietitian or nutritionist**

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# Special Health Matters

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All children and youth with special health care needs should have a consistent plan across all the environments where they live, study, play and work. An excellent strategy for incorporating nutrition goals and objectives outside the home is to work with the school system. In local communities, public schools provide a resource for children and youth with special health care needs through the Child and Adult Care Food Program which administers the National School Lunch and National School Breakfast Programs. Federal regulations permit modified school meals, at no extra cost, for students with disabilities or chronic medical problems who require special diets. Food substitutions and modified meals required for a medical or special dietary need are provided for individuals identified by the school system as having a disability. To receive this benefit, children and youth in special education programs must have a diet prescription from a physician. The prescription must include the following information:

- ***A statement identifying the disability, and how the disability affects the child's diet.***
- ***A statement identifying the major life activity affected by the disability.***
- ***A specific list of dietary changes, modifications or substitutions required for the diet.***

Children and youth with special health care needs who require a special diet but are not receiving special education services must have a written order from a recognized medical authority (e.g., physician, physician's assistant, nurse practitioner or other specialist identified by the state). For children and youth with chronic conditions such as diabetes or allergies who are not receiving special education services, determinations about providing meal modifications are made on a case-by-case basis. To make sure that nutrition goals and objectives are addressed in the child's educational program, it is important to have nutrition goals and objectives incorporated in the Individualized Education Plan or 504 Accommodation for children and youth with significant dietary and nutrition concerns.

## ♥ Can nutrition-related problems be prevented?

All health care professionals should be aware that children and youth with special health care needs are at increased risk for nutrition problems. Nutrition screening, early identification of problems, and nutrition education should become parts of routine medical care for children and youth with special health care needs. Beginning early in childhood, children with special needs should be screened for nutrition problems and caregivers should be provided with anticipatory guidance regarding the risk of nutrition problems and practical interventions for prevention, so as to avoid chronic nutrition-related problems.

## ♥ Resources

Children and youth with special health care needs may require many kinds of services to meet their general health and nutritional needs. In order to provide family-centered care, it is important to coordinate nutrition services with other medical appointments within the community. Dietitians with expertise in disabilities and special health care needs may be found in University Centers for Excellence in Developmental Disabilities, Title V-funded specialty clinics, pediatric units and outpatient departments of local hospitals, local health departments, dietitians in private practice, and local pediatric and public health nutrition practice groups of the American Dietetic Association.

Before prescribing specialized nutrition formulas and supplements for an individual, the dietitian or health care provider should make sure that the family has the resources to support the dietary recommendations or has access to food assistance services. Selected resources to explore include the following:

- ***Title V, Maternal and Child Health (MCH) program***
- ***Children and Youth with Special Health Care Needs (CYSHCN) program***
- ***Medical Assistance Services / Medicaid***
- ***Food Stamps Program***
- ***School Lunch and School Breakfast Programs***
- ***State Child Health Insurance Program (CHIP)***
- ***Private Insurance***