

ADOLESCENTS WITH SPECIAL HEALTH NEEDS

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BACKGROUND

Adolescents with special health care needs are at risk for nutrition-related health problems. This population is defined as “those (children/adolescents) who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and related services of a type or amount beyond that required by children generally.”¹ This is a broad definition that includes children with or at risk for physical and developmental disabilities, and chronic medical conditions.

Approximately 7-18% of children and adolescents ages birth to 18 years in the United States have a chronic physical, behavioral, developmental, or emotional condition causing limitation in activities, and/or requiring special care.^{2,3} Earlier studies by Newacheck report that about 6% of adolescents, ages 10 to 18 years, have a chronic condition that causes some disability or limitation in their activities of daily living.⁴ These statistics do not include the at-risk group of children and adolescents, however.

ETIOLOGY/CONTRIBUTING FACTORS

The etiology of developmental disabilities and special health care needs is complex. Adolescents may have physical impairments, developmental delays or chronic medical conditions that are caused by or 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 (e.g., lead, mercury)

For some conditions, the etiology is unknown. These conditions may cause physical, emotional, or behavioral problems that are challenging for the child and for the family. A team approach to services is often recommended to address the needs of these children. Nutrition may be one component of their care.^{5,6}

SIGNIFICANCE

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.^{7,8} Nutrition risk factors may be physical, biochemical, psychological or environmental in nature. Physical conditions such as a 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 other factors will have a strong impact on an individual's access to nutritious foods and reinforcements for following certain dietary regimens. One or more of these factors may put an adolescent with special needs at risk for nutrition problems.⁹

Common nutrition problems for the adolescent with special health care needs may include the following:^{6,9,10}

- 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 (e.g., rumination, pica, disordered eating, etc.)
- Dental and gum disease

Adolescents with special needs may experience one or more of these problems and require the attention of a registered dietitian for dietary counseling and guidance to prevent, treat or correct nutrition-related health problems.

SCREENING AND ASSESSMENT

Parents, caregivers, teachers, caseworkers, and health care providers can learn to screen for nutritional risk. Table 1 identifies the different data to collect to determine whether an adolescent is in need of further assessment of a nutrition problem. Adolescents with minor or no risk factors should be provided with basic nutrition education and anticipatory guidance to prevent nutrition problems.

TABLE 1
Nutrition Screening Parameters and Criteria for Referral for Adolescents
with Special Health Care Needs

| | Screening Data | Criteria for Referral to a Dietitian |
|-----------------------------------|--|--|
| Anthropometric^a | Weight Height Weight/height Body Mass Index Triceps skinfold (if atrophy of lower extremities > 85%) | Weight/height \leq 5 th percentile Weight/height \geq 95 th percentile Height/age \leq 5 th percentile BMI > 85 th percentile Triceps skinfold < 5 th percentile |
| Biochemical | Hemoglobin Hematocrit | Hemoglobin \leq 11 g/100 dL ^b Hematocrit \leq 34% |
| Clinical/Medical | Medical condition known to affect nutrition (e.g., vomiting, reflux), elimination problems, medications, and appetite or dental problems. | A diagnosis of heart disease, cancer, diabetes mellitus, HIV/AIDS, cerebral palsy, inborn errors of metabolism, malabsorption syndrome, cystic fibrosis, renal disease, or spina bifida. Recurring vomiting or reflux, chronic diarrhea or constipation, severe dental caries, long-term use of medications that interfere with nutrition, megavitamin use, or prolonged decrease in appetite with weight loss, or growth failure. |
| Diet/Feeding | Feeding method (e.g., by mouth, tube, parenteral) Therapeutic diet Ability to eat independently Significant food aversions or allergies | Tube feeding or parenteral nutrition Therapeutic diet Inability to self-feed Limited diet due to food aversions or allergies |
| Other | Parental or professional concern | Unresolved concerns regarding diet, nutrition or growth |

^aGrowth data should be recorded and plotted on standard growth charts; growth charts for specific conditions are available.

^bSet lab levels according to your program standards

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Sources: Screening tool used in PHS Region IX developed under SPRANS CE grant MCJ-009076 and MCHIP grant MCJ-065057. Los Angeles, CA: University Affiliated Program/ASC, Children's Hospital, 1994; Campbell MK, Kelsey KS. The PEACH survey: a nutrition screening tool for use in early intervention programs. J Am Diet Assoc 1994;94(10):1156-1158; Cialone J. Nutrition screening of school age children (presentation). Children and Youth Section, North Carolina Division of Women's and Children's Health, 1988; New Mexico Health and Environmental Health, Public Health Division, Nutrition Bureau. Criteria for referring of infants and children with handicapping conditions for nutrition services. Santa Fe, NM: New Mexico Health and Environmental Health, Public Health Division Nutrition Bureau, 1987; Isaacs JS, Cialone J, Horsley JW, Holland M, Murray P, Nardella M. Children with special health care needs: A community nutrition pocket guide. Dietetics in Developmental and Psychiatric Disorders and the Pediatric Nutrition Practice Group of the American Dietetic Association, and Ross Product Division of Abbott Laboratories, 1997.

Once a nutrition problem has been identified, the adolescent should be referred to a registered dietitian for a more in-depth nutrition assessment. Referral sources and knowledge of general nutrition resources are needed at this level of care. The assessment process will involve a more comprehensive evaluation of the problem and the development of a nutrition care plan.

The assessment process should evaluate the adequacy of the diet based on an evaluation of anthropometric data; biochemical indices and lab data; clinical findings; a dietary history or food frequency; and feeding skills. Chronic and disabling conditions and special health needs may impact nutritional health. Assessment areas that warrant attention for adolescents with special health care needs include:

Growth assessment

Since certain genetic conditions and disease processes may cause variations or disturbances in adolescent growth, it is important to monitor growth and to understand the factors that may cause variations on the growth curve. Growth rates may be different for certain genetic conditions, such as Turner syndrome and Prader-Willi syndrome. Individuals with these conditions tend to be short in stature. Active infections, malabsorption, or disease processes such as HIV infection and cystic fibrosis may impair weight gain. Adolescents with mobility problems, low muscle tone, and/or low metabolic rates (e.g., spina bifida, and Down syndrome) may have problems with excess weight gain.

Accuracy is important when recording growth data. For adolescents with special needs alternative measurements may be needed. Teens who cannot stand on a scale may require a sitting scale or a wheelchair scale. Recumbent length measurements or arm span measurements may be needed if an adolescent cannot stand upright for linear measurements. Individuals with contractures may require segmental length measurements on one side of the body. Body composition measurements, such as arm circumference and triceps skinfold thickness, may be needed to confirm the adequacy of fat and muscle mass. Alternative measurement methods should be documented so that they can be repeated at future visits.¹⁵

Some adolescents with special needs may not grow along the standard growth curves of the Centers for Disease Control and Prevention (CDC) growth charts since these charts are based on a population of typical children without disabilities or health concerns. Standard pediatric growth charts may be used to routinely track growth and monitor progress overtime, but practitioners should have a knowledge of the youth's disability, medical status, and genetic condition in order to accurately interpret growth parameters. Diagnosis-specific growth charts are available for certain conditions, and these can be helpful for comparing the adolescent to other individuals with the same diagnosis.¹⁵ (See RESOURCES at the end of this chapter.)

Energy intake

Evaluations of energy intake should examine the quality and quantity of the diet. Energy needs for youth with special needs vary widely and should be adjusted to support growth and development during adolescence. Table 2 provides energy calculations for certain diagnoses based on current practice and research. For some adolescents with special needs it is more appropriate to calculate energy needs based on height rather than weight to compensate for short stature. It should be emphasized that energy calculations are a starting point for estimating needs. Calorie estimates should be realistic based on the teen's diet history, medical status, and intake levels. Careful monitoring will determine if additional modification need to be made.¹⁵

TABLE 2
Selected Energy Calculations for Adolescents with Special Health Care Needs, by Diagnosis

| Medical Diagnosis | Energy Calculation |
|---|---|
| Spina Bifida ^{1,2} | For adolescents who are minimally active: To maintain weight: 9-11 kcal/cm height To promote weight loss: 7 kcal/cm height Adolescents who are not walking require approximately 25-50% less than ambulatory peers. |
| Prader-Willi syndrome ³ | To maintain growth within a growth channel: 10-11 kcal/cm height To create a slow rate of weight loss and support linear growth: 8.5 kcal/cm height |
| Cystic Fibrosis ⁴ | Calculate 120-150% of the recommended dietary allowance (RDA) for age and sex, depending on the severity of the disease. |
| Pediatric HIV Infections or AIDS ⁵ | Clinically stable youth usually have normal energy needs. Increased energy is needed for stress, fever, respiratory needs, and growth. Adding 150% of the recommended dietary intake (RDI) promotes weight gain, if diarrhea and malabsorption are not significant. |

Source: Compiled from: Ekvall SW. Myelomeningocele. In: Ekvall SW, ed. Pediatric nutrition in chronic diseases and developmental disorders: Prevention, assessment, and treatment. New York, NY: Oxford University Press, 1993;107-113; Heller L, Bujold C, Baer MT, Harris AB. Nutrition management of spina bifida. Nutrition focus for children with special health care needs 1996;11(3):1-8; Pipes P, Powell J. Preventing obesity in children with special health care needs. Nutrition focus for children with special health care needs 1996;11(6):1-8; Wooldridge NH. Pulmonary diseases. In: Samour PQ, Helm KK, Lang CE, eds. Handbook of pediatric nutrition. Gaithersburg: Aspen Publishers, Inc, 1999;453-464; Olsen LG, Cutroni R, Furuta L. Pediatric acquired immunodeficiency syndrome. In: Samour PQ, Helm KK, Lang CE, eds. Handbook of pediatric nutrition. Gaithersburg: Aspen Publishers, Inc., 1999;453-464.

Physical activity

Adolescents with special needs may have motor impairments and physical limitations that limit their physical expenditure of energy. In order to prevent problems with weight control, it is important to review their preferences for exercise and physical activity and to balance these with intake levels.

Elimination patterns

Many individuals with special needs have chronic elimination problems. Factors influencing bowel function include diet, hydration, mobility, activity level, muscle tone, medications, and health status. These factors need to be assessed by a multidisciplinary team in order to determine appropriate interventions for constipation or diarrhea.⁹

Feeding skills

Adolescents with special health needs may have developmental delays and neurologic impairments that affect their eating skills. Some individuals may require special feeding equipment to promote independent feeding. Some adolescents may need modified textures to prevent choking or gagging, and some may require tube feedings to supplement their oral intake or to replace oral intake if feeding by mouth is not safe or efficient.²¹ Adolescents with significant feeding problems may be referred to and followed by an interdisciplinary feeding team to manage complex feeding issues.

Long-term use of medications

Many individuals with special health care needs are on long-term medications to treat chronic medical conditions, such as anticonvulsant medications for seizure disorders, enzyme replacement therapy for individuals with cystic fibrosis or malabsorption, and antibiotics for infectious diseases. It is important to evaluate the long-term consequences of these medications in relation to appetite changes, and nutrient digestion, absorption and excretion. In addition, vitamin and mineral supplements should be reviewed for nutritional adequacy and safety. This is an area for nutrition education and counseling with adolescents and their caregivers. Dietary changes may be made to prevent or correct unnecessary side effects.⁹

Transition to adulthood

A goal for older children and adolescents is to take responsibility for their health care and diet, and to eventually achieve independence. An adolescent's ability to achieve self-sufficiency and independence will depend on his/her cognitive and developmental level. Developing a positive body image and taking control of one's diet can be challenging for an adolescent with disabilities or chronic conditions. Achieving independence with regard to nutrition and health is an important goal for health promotion and maintenance.²²

INTERVENTION

Nutrition services for an adolescent with special needs may require more specialized services to address complex nutrition issues and may involve an interdisciplinary team.¹⁰ The team approach allows for individuals from different disciplines to address the multifaceted problems that may impact nutrition and feeding. The adolescent and caregiver(s) should be key members of the team in the identification of problems and setting of priorities to be addressed in the treatment plan. Examples of the problems that may impact feeding and the respective team members to address these needs are outlined below:¹⁰

- Medical issues– physicians, nurses
- Neuromotor problems– physical therapists, occupational therapists, speech and language pathologists
- Behavior problems– psychologists
- Dental and oral health problems– dentists
- Financial issues, and community resources– social worker
- Quality and quantity of diet, growth– dietitian or nutritionist

Through the team approach a comprehensive plan is developed to address all the factors that may impact growth, development, and general health.

As a component of the nutrition assessment, a treatment plan addressing the dietary needs and changes should be developed in conjunction with the adolescent and his/her family with input from other team members. The goal of the treatment plan is to provide optimal nutrition to support growth, development, health and level of functioning. The nutrition plan is explained and initiated through nutrition education and counseling. A follow-up plan should be included for monitoring progress, modifying the plan, and setting new goals. All adolescents need to have a consistent plan across all the environments where they live, work, study, and play. Therefore an important strategy is to have similar goals for nutrition at home, school, and other areas of their lives.

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 teens with special 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, adolescents in special education programs must have a diet prescription from a physician. The prescription must include the following information (see Figure 1 for a sample diet prescription form):²³

- A statement identifying the disability, and how the disability affects the adolescent'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.

Adolescents 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 adolescents 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 issues are addressed in the adolescent's educational program, it is important to have nutrition goals and objectives incorporated in the Individualized Education Plan or 504 Accommodation for youth with significant dietary and nutrition concerns.²⁴

PREVENTION

All health care professionals should be aware that adolescents 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 adolescents 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 health problems.

Of interest to many practitioners in the field of pediatrics and developmental disabilities and special needs, is the importance of prenatal care and healthy diets in the prevention of specific disabilities. Recent evidence shows that the intake of folate, a water-soluble B vitamin, may significantly reduce the incidence of neural tube defects (i.e., anencephaly, spina bifida, etc.). National and international vitamin and dietary studies of women who have had a previous neural tube defect (NTD)-affected pregnancy, and those not at risk indicate that there is an association between folate consumption and the prevention of neural tube defects. Evidence shows a reduction by 60-86% of all cases of NTDs with periconceptional folate intake. In utero the neural tube forms between day 18-20 of gestation and closes between days 24-27. During this time period, many women are unaware that they are pregnant. Public health efforts have focused on folate intake throughout the childbearing years. In 1992 the Public Health Service issued guidelines that all women of child-bearing age who are capable of becoming pregnant should consume 0.4 mg/day (or 400 mcg/day) of folate to reduce the incidence of NTDs by 50%.²⁵ Women with a previous history of an NTD-affected pregnancy were encouraged to take 4.0 mg/day at least three months prior to conception and for the first three months of pregnancy as a preventive measure, under the supervision of a physician. Adequate dietary folate intake is a significant area of nutrition and the prevention of disabilities.

REFERRAL

Adolescents with special 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.⁹

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. Programs that provide nutrition services and benefits will vary from state to state. Selected resources to explore include the following:

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

RESOURCES

Diagnosis Specific Growth Charts Covering the Adolescent Years

General

Saul RA, Stevenson, RE. Growth references: third trimester through adulthood. 2nd ed. Greenwood, SC: Greenwood Genetic Center, 1998.

Achondroplasia

Horton WA, Rotter JI, Rimoin DL, Scott CI, Hall JG. Standard growth curves for achondroplasia. *J Pediatr* 1978;93(3): 435-438.

Cerebral Palsy

Spender QW, Cronk CE, Charney EB, Stallings VA. Assessment of linear growth of children with cerebral palsy: Use of alternative measures of height or length. *Dev Med Child Neur* 1989; 31(2):206-214.

Down Syndrome

Cronk, C, Crocker, AC, Pueschel SM, Shea, AM, Zachai E, Pickens G, Reed RB. Growth charts for children with Down syndrome: 1 month to 18 years of age. *Pediatr* 1988;81(1):102-110.

Fragile X Syndrome

Butler MG, Brunschwig A, Miller LK, Hagerman RJ. Standards for selected anthropometric measurements in males with fragile X syndrome. *Pediatr* 1992;89:1059-1062.

Muscular Dystrophy

Griffiths RD, Edwards RH. A new chart for weight control in Duchenne muscular dystrophy. *Arch Dis Child*. 1988; 63(10):1256-1258.

Myelomenigocele

Ekvall S, Schwiegeraht L, Bigley B, Beck C, Leonti G. Preliminary growth charts for myelomeningocele with NCHS standard growth curve. In: Ekvall SW, ed. *Pediatric nutrition in chronic diseases and developmental disorders: prevention, assessment, and treatment*. New York: Oxford University Press, 1993:435-436.

Prader-Willi Syndrome

Butler MG, Meaney FJ. Standards for selected anthropometric measurements in Prader-Willi syndrome. *Pediatr* 1991;88(4):853-860.

Turner Syndrome

Lyon AF, Preece MA, Grant DB. Growth curves for girls with Turner syndrome. *Arch Dis Child* 1985;60(10):932-935.

General Information

Children with special health care needs: nutrition care handbook. (2004). Lucas B, Feucht SA, Grieger LE (Editors). Pediatric Nutrition Practice Group and Dietetics in Developmental and Psychiatric Disorders Practice Group of the American Dietetic Association. ISBN: 0-88091-346-0. Contact: The American Dietetic Association at <http://www.eatright.org> or 1-800 877-1600. (\$39 for nonmembers; \$30 for members)

Nutrition focus for children with special health care needs. (Newsletter, \$36 for 6 issues/year). Contact: Nancy Saunders, Nutrition Focus, CHDD, University of Washington, Box 357920, Seattle, WA 98195. Telephone: 206-616-2831.

Klein MD, Delaney TA, Feeding and nutrition for the child with special needs. Tucson, AZ: Therapy Skill Builders; 1994. Contact Harcourt Assessment at 800-866-4446.

CARE: special nutrition for kids. Alabama Department of Education, School Nutrition Programs, Federal Administrative Services, Montgomery, AL; 1999 Revised. (A video and workbook targeted for school food service managers, and school personnel.) Contact: National Food Service Management Institute, P.O. Drawer 188, University, MS 38677-0188. Telephone: 800-321-3054.

Accommodating children with special dietary needs in school nutrition programs: guidance for school food service staff. US Department of Agriculture, Food and Consumer Services: Alexandria, VA; 1995. Contact: Regional USDA Office.

Ekvall SW, ed. *Pediatric nutrition in chronic diseases and developmental disorders: prevention, assessment, and treatment*. New York: Oxford University Press; 1993.

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18. Pipes P, Powell J. Preventing obesity in children with special health care needs. *Nutrition focus for children with special health care needs* 1996;11(6):1-8.

19. Wooldridge NH. Pulmonary diseases. In: Samour PQ, Helm KK, Lang CE, eds. Handbook of pediatric nutrition. Gaithersburg: Aspen Publishers, Inc, 1999;315-353.
20. Olsen LG, Cutroni R, Furuta L. Pediatric acquired immunodeficiency syndrome. In: Samour PQ, Helm KK, Lang CE, eds. Handbook of pediatric nutrition. Gaithersburg: Aspen Publishers, Inc., 1999;453-464.
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