

Nutrition for Children with Special Health Care Needs

Resource Notebook

MODULE 1: Growth Assessment

LEARNING OBJECTIVES

After completing this module, you will have the skills and resources to:

- Describe techniques to obtain accurate anthropometric data for children with special health care needs
- Identify tools used for growth assessment and understand the origin of these tools
- Describe the influence of special conditions on growth
- Use appropriate reference data and published information to interpret growth data

RESOURCES

Measurement Techniques

Anthropometric Standardization Reference Manual. Lohman TG, Roche AF, Martorell R, eds. *Anthropometric Standardization Reference Manual*. Champaign, Ill: Human Kinetics Books, 1988. ISBN 0-87322-331-4. This book describes many measurement techniques. It is out of print, however, copies are sometimes available through college and university bookstores. Several online retailers, including <http://alibris.com> and <http://bookfinder.com>, sometimes have this book in stock.

CDC/MCHB Growth Chart Tutorials: Measurement Techniques. Centers for Disease Control and Prevention and the Maternal and Child Health Bureau. *Growth Charts Training*. 2001. The CDC and MCHB have developed tutorials to accompany the 2000 CDC Growth Charts. These tutorials are aimed at health care professionals. Modules cover equipment, measurement technique, and developing and rating your technique. For information about accessing the tutorials, visit <http://depts.washington.edu/growth>.

Tools for Assessment

CDC Growth Charts. Centers for Disease Control and Prevention (CDC). Information about the 2000 CDC Growth Charts, and downloadable versions of the charts are available on the CDC website: <http://www.cdc.gov/growthcharts>.

The New Childhood Growth Charts. Roberts B, Dallal GE. The new childhood growth charts. *Nutrition Reviews*. Volume 59, Number 2, pages 31-36. February 2001. This article is posted to the PacWest MCH Distance Learning Network website, <http://depts.washington.edu/pwdlearn/pdfs/childcharts.pdf>, with permission from the International Life Science Institute.

Frequently Used Guidelines: Anthropometrics and growth. Guidelines for interpretation of growth are presented.
<http://depts.washington.edu/nutrpeds/fug/growthtoc.htm>.

CDC/MCHB Growth Chart Tutorials: Growth Assessment. Centers for Disease Control and Prevention and the Maternal and Child Health Bureau. *Growth Charts Training*. 2001. The CDC and MCHB have developed tutorials to accompany the 2000 CDC Growth Charts. These tutorials are aimed at health care professionals. Modules cover use and interpretation of the charts, including BMI. For information about accessing the tutorials, visit <http://depts.washington.edu/growth>.

Other Growth Charts. Charts with data for secondary measurements and alternatives to height and length are available.

- Crown-rump Length. Crown-rump length. McCammon RW, ed. *Human Growth and Development*. Springfield, Ill: Charles C Thomas, 1970. Longitudinal data from 75 females and 75 males are presented.
- Prediction of Stature from Knee Height. Chumlea WC, Guo SS, Steinbaugh ML. Prediction of stature from knee height for black and white adults and children with applications to mobility-impaired or handicapped persons. *J Am Diet Assoc*. 1994; 94(12): 1385-1388. This article presents data collected during 1960-1970 from children 6-12 years of age. The population was 85% Caucasian.
- Sitting Height. Hamill PV, et al. Body weight, stature and sitting height. *US Vital and Health Statistics, Series 11, #126*; Publication No. HSM 73-1606. Washington DC: US Government Printing Office, 1973. These tables (sitting height for age) are based on the NCHS 1977 population (age 1-18 years).
- Triceps Skinfold and Upper Arm Circumference. Frisancho AR. New norms of upper limb fat and muscle areas for assessment of nutritional status. *Am J Clin Nutr*. 34: 2540-2545, 1981. This article provides age- and sex-specific percentiles for triceps skinfold, upper arm circumference, arm muscle area, and arm fat area based on a cross-sectional sample of 19,097 white subjects age 1 to 74 years.

Influence of Special Health Care Needs

Charts/Tables Used to Monitor Growth of Children with Special Health Care Needs.

Reprinted with permission from: Nardella M, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2001. This table describes charts and tables that are often used to monitor the growth of children with special health care needs. It is included at the end of this section. To order a hard copy, contact the Washington State Department of Health, Revenue Section, PO Box 1099, Olympia, WA 98504 or visit the Washington State Nutrition for Children with Special Health Care Needs website: <http://depts.washington.edu/cshcnut>. This publication can also be downloaded from the WA DOH website:

<http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>.

Gaining and Growing. The Gaining and Growing website presents information about the influence of prematurity on anthropometric assessment, including catch-up growth and incremental growth. Visit:

<http://staff.washington.edu/growing/Assess/index~3.htm>.

North American Growth in Cerebral Palsy Project. North American Growth in Cerebral Palsy Project website. One activity of this project is to collect data about the growth of persons with cerebral palsy. The project website also lists some resources around growth, measurement technique, and interpretation. Visit:

<http://www.people.virginia.edu/~mon-grow/>.

Using Growth Data to Make Clinical Decisions

Assessment of Growth: Equipment, techniques and growth charts. Feucht S. Assessment of growth: Part 1, equipment, technique and growth charts.

Nutrition Focus. 15(2). 2000. To order, visit

http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

Assessment of Growth: Interpretation of growth. Trahms C, Feucht S.

Assessment of growth: Part 2, interpretation of growth. *Nutrition Focus*. 15(3 and 4). 2000. This article presents case studies using the 2000 CDC Growth Charts to evaluate growth. To order, visit

http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

Anthropometrics. Murphy K. Anthropometrics. In: Nardella M, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2001. This chapter describes techniques for weighing and measuring children and presents some guidelines for interpreting measurements. Ordering information is above. (See “Charts/Tables Used to Monitor Growth of Children with Special Health Care Needs.”)

Table 2-2: Charts/Tables Used to Monitor Growth of Children with Special Health Care Needs[†]

Growth Chart	Study sample information	Ages	Parameters	Limitations	Use with CDC
NCHS (1977) ¹⁷	20,000 children, 1934-64; NHES and NHANES I; 5 th -95 th %iles	0-3 years	<ul style="list-style-type: none"> weight/age length/age OFC/age weight/length 	Data is longitudinal for infants and cross-sectional for children	
NCHS (1977) ¹⁷	20,000 children 1934-64; NHES and NHANES I; 5 th -95 th %iles	2-18 years	<ul style="list-style-type: none"> weight/age height/age weight/height 	Data is cross-sectional for children	
CDC (2000) ¹	Previous data plus NHANES III data; 3 rd -97 th %iles	0-3 years	<ul style="list-style-type: none"> weight/age length/age OFC/age weight/length 		
CDC (2000) ¹	Previous data plus NHANES III data; 3 rd -97 th %iles	2-20 years	<ul style="list-style-type: none"> weight/age height/age weight/height (2-6 years) BMI/age 		
Crown-rump ¹⁸	~75 females, 75 males			Longitudinal data	Use with CDC weight/ age
Sitting height ¹⁹	NCHS 1977 population	1-18 years	<ul style="list-style-type: none"> sitting height/age 	Caucasian and African American children only	Use with CDC weight/ age
Knee height ²⁰	13,821 ambulatory children NHES I,II,III, 1960-70	6-12 years	<ul style="list-style-type: none"> knee height/age 	Use equation for race (85% Caucasian children); Difficult to do	Use with CDC weight/ age
Incremental growth ⁹	Children who grew "close" to NCHS 1977	6-36 mos 2-18 years	<ul style="list-style-type: none"> weight/age stature/age 	Caucasian children only	Use with CDC for weight/age, length or height/age, weight/length or height

[†] All charts have sex-specific versions for male and female children (except for Turner syndrome charts).

Growth Chart	Study sample information	Ages	Parameters	Limitations	Use with CDC
Triceps skinfold thickness, upper arm circumference ¹⁰	NCHS 1977 population	2-18 years	<ul style="list-style-type: none"> triceps skinfold/age upper arm circumference/ age upper arm fat area/age 	Use after age 2 years, Caucasian children only	Use with CDC weight/age, length or height/age, weight/length or height, or BMI/age
Mid-arm circumference; triceps skinfold, subscapular skinfold thicknesses ^{13,14,15}	NCHS 1977 population	2-18 years		Use after age 2 years	Use with CDC weight/age, length or height/age, weight/length or height, or BMI/age
Parent-specific adjustment for length/stature ¹¹	586 parent-child pairs (Fels data) and 16,000 serial length and height measurements	0-36 mos 3-18 years		Note parent height on chart	Use with CDC weight/age, length or height/age, weight/length or height, or BMI/age
Achondroplasia ²²	189 males, 214 females	0-18 years	<ul style="list-style-type: none"> height/age height velocity/age upper, lower segment lengths/age OFC/age 	Small sample size, especially children over 10 years	Compare to CDC weight/age, length or height/ age; use with CDC for weight/length or height or BMI/age
Cerebral palsy ²³	360 children (males and females), 0-120 months with quadriplegia	0-10 years	<ul style="list-style-type: none"> length/age weight/age weight/length 	Both longitudinal and cross-sectional data, small sample size, for spastic quadriplegia only [†]	Use with CDC weight/age, length or height/age, weight/length or height or BMI/age
Down syndrome ²⁴	Longitudinal data; 400 males, 300 females; 1960-1986	1-36 mo 2-18 years	<ul style="list-style-type: none"> weight/age length or height/age 	Included children with congenital heart disease, reflects tendency to be overweight	Use with CDC weight/age, length or height/ age, weight/length or height, or BMI/age

[†] These growth charts should be used only with children who have cerebral palsy with spastic quadriplegia and may underestimate the growth for a child with mild cerebral palsy or without spastic quadriplegia. More information about growth and children with cerebral palsy can be found at the North American Growth in Cerebral Palsy Project website: <http://www.people.virginia.edu/~mon-grow/healthcare/home.html>

Section 1 – Determination of Nutrition Status

Growth Chart	Study sample information	Ages	Parameters	Limitations	Use with CDC
Noonan syndrome ²⁵	64 males, 48 females	0-20 years	<ul style="list-style-type: none"> height/age 	Small sample size	Compare to CDC; use CDC for weight/ age, length or height/age, weight/length or height or BMI/age
Prader Willi syndrome ²⁶	56 males, 36 females	3-24 years	<ul style="list-style-type: none"> height/age 	Longitudinal and cross-sectional data, small sample size	Compare to CDC; use CDC for weight/ age, weight/ height, BMI/age
Turner syndrome ²⁷	366 females; pooled data; no hormone treatment	2-19 years	<ul style="list-style-type: none"> height/age 	Small sample size, unequal age distribution	Use with CDC for weight/age, height/ age, weight/height, BMI/age
Williams syndrome ²⁸	61 females, 47 males	0 to 18 years	<ul style="list-style-type: none"> weight/age height/age OFC/age 	Retrospective and cross-sectional data, small sample size	Use with CDC for weight/length or height, BMI/age

1. Kuczumski RJ, Ogden CL, Grummer-Strawn LM, et al. CDC growth charts: United States. *Advance Data from Vital and Health Statistics*; no. 314. Hyattsville Maryland: National Center for Health Statistics. 2000. Available at <http://www.cdc.gov/growthcharts/>. Accessed October 30, 2000.
9. Roche AF, Himes JH. Incremental growth charts. *Am J Clin Nutr*. 1980;33:2041-2052.
11. Himes JH, Roche AF, Thissen D, Moore WM. Parent-specific adjustments for evaluation of recumbent length and stature of children. *Pediatrics*. 1985;75(2): 304-313.
13. Frisancho AR. New norms of upper limb fat and muscle areas for assessment of nutritional status. *Am J Clin Nutr*. 1981;34:2540-2545.
14. Gurney JM, Jelliffe DB. Arm anthropometry in nutritional assessment: a nomogram for rapid calculation of muscle circumference and cross-sectional muscle and fat areas. *Am J Clin Nutr*. 1973; 26:912-915.
15. Tanner JM, Whitehouse RH. Revised standards for triceps and subscapular skinfolds in British children. *Arch Dis Child*. 1975;50:142-145.
17. Hamill PV, Drizd TA, Johnson CL, Reed RB, Roche AF, Moor WM. Physical growth: National Center for Health Statistics percentiles. *Am J Clin Nutr*. 1979;32(3):607-629.
18. McCammon RW, ed. *Human Growth and Development*. Springfield, IL: Charles C Thomas; 1970.
19. Hamill PV, et al. Body weight, stature, and sitting height. *US Vital and Health Statistics, Series 11, #126*; Publication No. HSM 73-1606. Washington DC: US Government Printing Office; 1973.
20. Chumlea WC, Guo SS, Steinbaugh ML. Prediction of stature from knee height for black and white adults and children with application to mobility-impaired or handicapped persons. *J Am Diet Assoc*, 1994; 94(12):1385-1388.
21. Johnson CL, et al. Basic data on anthropometric measurement and angular measurements of the hip and knee joints for selected age groups, 1-74 years of age, United States, 1971-1975. *US Vital and Health Statistics, Series 11, #219*; Publication No. PHS 81-1669. Washington DC: US Government Printing Office; 1981.
22. Horton WA, Rotter JI, Rimoin DL, Scott CI, Hall JG. Standard growth curves for achondroplasia. *J Pediatr*. 1978;93(3):435-438.
23. Krick J, Murphy-Miller P, Zeger S, Wright E. Pattern of growth in children with cerebral palsy. *J Am Diet Assoc*. 1996;96(7):680-685.
24. Cronk C, Crocker AC, Puschel SM, Shea AM, Zackai E, Pickens G, Reed RB. Growth charts for children with Down syndrome: 1 month to 18 years of age. *Pediatrics*. 1988;81(1):102-110.
25. Witt DR, et al. Growth curves for height in Noonan syndrome. *Clin Genet*. 1986; 30:150-153.
26. Holm V. In: Greenswag LR, Alexander RC. *Management of Prader-Willi Syndrome, 2nd ed*. New York: Springer-Verlag; 1995.
27. Ranke MB, Pfluger H, Rosendahl W, Stubbe P, Enders H, Bierich JR, Majewski F. Turner syndrome: spontaneous growth in 150 cases and review of the literature. *Eur J Pediatr*. 1983;141(2):81-88.
28. Morris CA, Demsey SA, Leonard CO, Dilts C, Blackburn BL. Natural history of Williams syndrome: physical characteristics. *J Pediatr*. 1988;113(2):318-326.

MODULE 2: Dietary Assessment and Determining Individual Needs

LEARNING OBJECTIVES

After completing this module, you will have the skills and resources to:

- Understand the methods used to establish standards and recommendations for nutrient intake
- Identify factors that alter nutrient needs
- Obtain accurate dietary intake data
- Evaluate an individual's dietary data for nutritional adequacy

RESOURCES

Obtaining Accurate Dietary Intake Data

Nutrition Questionnaires for Infants, Children, and Adolescents. Appendices A, B, and C in Story M, Holt K, Sofka D, eds. 2002 *Bright Futures in Practice: Nutrition* (2nd ed.). Arlington, VA: National Center for Education in Maternal and Child Health. Questionnaires, along with guidelines for interpreting answers to the questionnaires are included. This publication is available online at <http://www.brightfutures.org> and print copies can also be ordered.

Methods Used to Establish Recommendations for Intake

Food and Nutrition Board: Scientific Evaluation of DRIs. This website describes the development of the DRIs and includes pdf versions of panel reports and summary tables. <http://www.iom.edu/project.asp?id=4574>.

Identifying Factors That Affect Nutrient Needs

Medications. Medications. In: Harris AB, Blyler EM, Baer MT. *Nutrition Strategies for Children with Special Needs*. USC University Affiliated Program, Childrens Hospital Los Angeles. 1999. This chapter describes many of the medications that a child with special needs might take, and outlines plans to minimize medication-nutrient interactions.

Medication-nutrient Interactions. Blank S, Harper E. Medication-nutrient interactions. In: Nardella M, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2001. This chapter reviews many of the medications (and the medication-nutrient interactions that may be present) commonly used in the treatment of children with special health care needs. To order, contact the Washington State Department of Health, Revenue Section, PO Box 1099, Olympia WA 98504 or visit the Washington State Nutrition for Children with Special Health Care Needs website: <http://depts.washington.edu/cshcnut>. The publication can also be downloaded from the WA DOH website: <http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>.

Evaluating the Dietary Data of Individuals for Nutritional Adequacy

Dietary Reference Intakes: Applications in Dietary Assessment. Institute of Medicine. *Dietary Reference Intakes: Applications in Dietary Assessment*. Food and Nutrition Board. Washington, DC National Academy Press, 2000. This document describes the use of the DRIs in assessing the intakes of groups and individuals and provides some guidelines for interpretation. <http://www.nap.edu/books/0309071836/html> or can be ordered from the National Academy Press at <http://www.nap.edu/catalog/9956.html>.

The Food and Nutrition Information Center (FNIC). The FNIC website has information about food and nutrition, including links to nutrient composition information, a searchable nutrient database, dietary guidelines, and food guide pyramids. FNIC is part of the US Department of Agriculture. <http://www.nal.usda.gov/fnic>

REFERENCES

Conway JM, Ingwersen LA, Vinyard BT, Moshfegh AJ. Effectiveness of the US Department of Agriculture 5-step multiple-pass method in assessing food intake in obese and nonobese women. *Am J Clin Nutr*. 2003;77:1171-1178.

Institute of Medicine. *Dietary Reference Intakes for Calcium, Phosphorus, Magnesium, Vitamin D, and Fluoride*. Food and Nutrition Board. Washington, DC: National Academy Press, 1997. The report is available on-line: <http://www.nap.edu/catalog/5776.html>.

Institute of Medicine. *Dietary Reference Intakes for Energy, Carbohydrate, Fiber, Fat, Fatty Acids, Cholesterol, Protein, and Amino Acids (Macronutrients)*. Food and Nutrition Board. Washington DC: National Academy Press, 1998. This report is available on-line. A hard copy can be ordered from <http://www.nap.edu/catalog/6015.html>.

Institute of Medicine. *Dietary Reference Intakes for Thiamin, Riboflavin, Niacin, Vitamin B6, Folate, Vitamin B12, Pantothenic Acid, Biotin, and Choline*. Food and Nutrition Board. Washington, DC: National Academy Press, 1998. This report is available on-line: www.nap.edu/catalog/6015.html.

Institute of Medicine. *Dietary Reference Intakes for Vitamin A, Vitamin K, Arsenic, Boron, Chromium, Copper, Iodine, Iron, Molybdenum, Nickel, Silicon, Vanadium and Zinc*. Food and Nutrition Board. Washington, DC: National Academy Press, 2001. This report is available on-line: <http://www.nap.edu/catalog/10026.html>.

Institute of Medicine. *Dietary Reference Intakes for Vitamin C, Vitamin E, Selenium, and Carotenoids*. Food and Nutrition Board. Washington, DC: National Academy Press, 2000. This report is available on-line: <http://books.nap.edu/catalog/9810.html>.

Johnson RK, Driscoll P, Goram MI. Comparison of multiple-pass 24-hour recall estimates of energy intake with total energy expenditure determined by the doubly labeled water method in young children. *J Am Diet Assoc*. 1996;96(11):1140-1144.

Trumbo P, Yates AA, Schlicker S, Poos M. Dietary reference intakes: vitamin A, vitamin K, arsenic, boron, chromium, copper, iodine, iron, manganese, molybdenum, nickel, silicon, vanadium, and zinc. *J Am Diet Assoc*. 101(3): 294-301; 2001. This article presents a discussion of the development of the DRIs and includes a table of the DRIs as of 2001. It is available on-line to ADA members at: <http://www.eatright.org>. Login with your ADA number, then follow the links to the Journal.

Nutrition Strategies for Children with Special Health Care Needs. Harris AB, Blyler EM, Baer MT. *Nutrition Strategies for Children with Special Needs*. USC University Affiliated Program, Childrens Hospital Los Angeles. 1999. This manual provides guidelines for nutrition screening and strategies for ten nutrition-related health concerns. Resources and educational materials are also included.

Nutritional Assessment. Bessler S. Nutritional assessment. In: Samour PQ, Helm KK, Lang CE. *Handbook of Pediatric Nutrition*, 2nd ed. Gaithersburg, MD. 1999.

Reilly JJ, Montgomery C, Jackson D, MacRitchie J, Armstrong J. Energy intake by multiple pass 24h recall and total energy expenditure: a comparison in a representative sample of 3-4-year olds. *Br J Nutr*. 2001;86(5):601-605.

MODULE 3: Feeding Skills

LEARNING OBJECTIVES

After completing this module, you will have the skills and resources to:

- Understand typical feeding development and the development of feeding and eating skills and behaviors
- Understand nutrition management of enteral (tube) feedings, including a basic understanding of equipment
- Describe appropriate routes of feeding for specific situations
- Identify appropriate formulas for specific situations

RESOURCES

Feeding Skills, Behavior, and Assessment of Feeding Skills

Questions about food patterns and feeding skills. This table outlines questions that may be useful in assessing food patterns and feeding skills. It is included at the end of this section.

Suggested Serving Sizes for Children. This table outlines suggested serving sizes for children. It is included at the end of this section.

Feeding and Eating. Feeding and eating. In: Isaacs JS, et al. *Children with Special Health Care Needs: A community pocket guide*. Dietetics in Developmental and Psychiatric Disorders and the Pediatric Nutrition Practice Group of The American Dietetic Association and Ross Products Division. 1997. This chapter outlines normal feeding skill development and discusses assessment of and interventions for some feeding problems. This publication is currently unavailable. A 2nd edition is under development.

Oral-motor Feeding Problems. Glass RP. Oral-motor feeding problems. In: Nardella M, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2001. This chapter describes the developmental sequence of oral-motor and self-feeding skills and outlines assessment, intervention, and evaluation of oral-motor feeding problems. To order, contact the Washington State Department of Health, Revenue Section, PO Box 1099, Olympia WA 98504 or visit the Washington State Nutrition for Children with Special Health Care Needs website: <http://depts.washington.edu/cshcnut>.

The publication can also be downloaded from the WA DOH website:
<http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>.

Pre-Feeding Skills: A comprehensive resource for feeding development.

Morris SE and Klein MD. *Pre-Feeding Skills: A comprehensive resource for feeding development*. Therapy Skill Builders, 2000. This revision of the 1987 book includes information about normal feeding development and factors that influence feeding. Assessment and treatment are discussed. Available from the Psychological Corporation <http://marketplace.psychcorp.com> (Item number 076-1674-071)

Feeding and Swallowing Disorders in Infancy. Wolf LS and Glass RP.

Feeding and Swallowing Disorders in Infancy. Therapy Skill Builders 1992. This text addresses diagnosis, evaluation, treatment and follow-up for infants with feeding dysfunction. Available from the Psychological Corporation:
<http://marketplace.psychcorp.com> (Item number 076-1641-904)

Collecting and Assessing Food Intake Information. Pipes PL, Glass RP.

Collecting and assessing food intake information. In: Trahms CM and Pipes PL. *Nutrition in Infancy and Childhood*, 6th ed. WCB/McGraw-Hill. 1997. A table in this chapter, Screening of Eating Abilities, lists guidelines for identifying problems with eating and feeding.

Feeding Infants: A guide for use in the Child Nutrition Programs. United

States Department of Agriculture Food and Nutrition Service. *Feeding Infants: A guide for use in the Child Nutrition Programs*. USDA FNS-258. 2001. The 105-page guide includes information on infant development, nutrition for infants, breastfeeding and formula feeding, preventing tooth decay, feeding solid foods, drinking from a cup and choking prevention. This guide was distributed to child care centers, sponsors of CACFP homes, and state agencies, and is available in electronic format at: http://www.fns.usda.gov/tn/Resources/feeding_infants.html.

How to Get Your Kid to Eat...But Not Too Much. Satter E. *How to Get Your*

Kid to Eat...But Not Too Much. Bull Publishing. 1987. This book is written for parents and discusses the impact of child development and parent-child relationships on feeding dynamics from infancy to adolescence. It is available at bookstores, or directly from the publisher: Bull Publishing,
<http://www.bullpub.com>.

Child of Mine, Feeding with Love and Good Sense. Satter E. *Child of Mine,*

Feeding with Love and Good Sense. Bull Publishing. 2000. This is a nutrition and feeding reference book for parents of children under 4 years of age. It is available at bookstores, or directly from the publisher: Bull Publishing,
<http://www.bullpub.com>.

Nutrition and Feeding for Infants and Children, Handout Masters. Satter E. *Nutrition and Feeding for Infants and Children*, Handout Masters. Ellyn Satter Associates. 1995 (with 1997 updates). Information is taken from *Child of Mine* and *How to Get Your Kid to Eat*. This set of handouts is appropriate for families, educators, and health care providers. It is available from Ellyn Satter Associates, <http://www.ellynsatter.com>.

Influence of Special Health Care Needs

Project SPOON: Special Program of Oral Nutrition for Children with Special Needs. Tluczek A, Sondel S. *Project SPOON: Special Program of Oral Nutrition for Children with Special Needs*. 1991. This report of a 3-year pilot project describes a multidisciplinary approach to feeding problems with children with special health care needs. It is available through the HRSA Information Center: <http://www.ask.hrsa.gov>, item code: MCHE016.

Dietary and Feeding Needs of Children with Cleft Lips and/or Palates. Wong J, Cohea M. Dietary and feeding needs of children with cleft lips and/or palates. *Nutrition Focus*. 2001 16(4). This article presents some of the nutrition- and feeding-related concerns associated with cleft lip and palate and presents some intervention strategies. To order, visit http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

Guidelines for the Use of Thickeners in Foods and Liquids. Feucht S. Guidelines for the use of thickeners in foods and liquids. *Nutrition Focus*. 1995; 10(6). To order, visit http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

Diagnosis and Treatment of Feeding Disorders in Children with Developmental Disabilities. Schwarz SM, Corredor J, Fisher-Medina J, Cohen J, Rabinowitz S. Diagnosis and treatment of feeding disorders in children with developmental disabilities. *Pediatrics*. 2001; 108(3): 671-676. An abstract is available on-line; non-subscribers can purchase a copy of the article: <http://www.pediatrics.org/cgi/reprint/108/3/671>.

Management of Tube Feedings

Enteral Feeding. Pederson A. Enteral feeding (Tube feeding). In: Nardella M, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2001. This chapter outlines assessment, intervention, and evaluation guidelines for determining when an enteral feeding should be used and for evaluating a child who is receiving an enteral tube feeding. To order, contact the Washington State Department of

Health, Revenue Section, PO Box 1099, Olympia WA 98504 or visit the Washington State Nutrition for Children with Special Health Care Needs website: <http://depts.washington.edu/cshcnut>. The publication can also be downloaded from the WA DOH website: <http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>.

Technical Aspects of Enteral Feeding. Pederson A. Technical aspects of enteral feeding. In: Nardella M, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2001. This appendix provides details about some of the technical aspects of tube feeding, including routes of administration, formulas, and complications associated with tube feeding. To order, contact the Washington State Department of Health, Revenue Section, PO Box 1099, Olympia WA 98504 or visit the Washington State Nutrition for Children with Special Health Care Needs website: <http://depts.washington.edu/cshcnut>. The publication can also be downloaded from the WA DOH website: <http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>.

Non-oral Enteral Feedings. Non-oral enteral feeding. In: Isaacs JS, et al. *Children with Special Health Care Needs: A community pocket guide*. Dietetics in Developmental and Psychiatric Disorders and the Pediatric Nutrition Practice Group of The American Dietetic Association and Ross Products Division. 1997. This publication is currently unavailable. A 2nd edition is under development.

Pediatric Formula Update. Hattner J. Pediatric formula update 2001. *Nutrition Focus* 2001 16(3). This article describes some of the commercial formulas available for infants and children. To order, visit http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

QUESTIONS ABOUT FOOD PATTERNS AND FEEDING SKILLS

The following questions are often useful for eliciting information about a child's food pattern:

- How often does the infant breastfeed?
- How frequently is the infant/child fed?
- How is formula prepared?
- What is the typical meal pattern?
- How much does he eat at one time?
- What supplements are used (energy, protein, enteral, vitamin, mineral)?
- Does the child have food allergies or intolerances or are there any food restrictions?

A discussion about behaviors, relationships, and attitudes related to food and eating might be started with these questions:

- What foods are preferred? Disliked?
- Can your child communicate hunger? Thirst?
- Who is present at mealtimes?
- Are mealtimes pleasant?
- Describe your child's appetite.
- Is your child interested in eating?
- Do you think your child is underweight? Overweight?
- Do you think your child eats too much? Too little?



The following questions may be useful for assessing a child's feeding skills:

- What types of foods does your child eat?
 - Describe the texture
 - Describe the consistency
 - How many times does your child eat each day?

- Do you have concerns about your child's feeding skills?
 - Does your child feed himself? With fingers? With utensils?
 - Does your child have problems chewing or swallowing? Gagging or choking?
 - Are there specific foods or textures that your child has difficulty with?
 - Does your child choke while eating? If so, how often does this happen?

- Can your child clearly communicate hunger and thirst?

- How does your child respond when food is offered?

Asking a caregiver about a child's feeding history can also provide useful information:

- When were solid foods introduced?
- What types of solid foods were introduced?
- When did your child learn to drink from a cup?
- What was your child's reaction to solids? To finger-feeding? To utensils? To the cup?



Suggested Serving Sizes for Children

These suggestions are not necessarily appropriate for all children (and may be inappropriate for some children with medical conditions that greatly affect nutrient needs). They are intended to serve as a general framework that can be individualized based on a child's condition and growth pattern.

	Suggested serving size for child 1-3 years of age	Suggested serving size for child 4-6 years of age	Suggested serving size for child 7-10 years of age	Suggested serving size for child 11-18 years of age
Grain Products	<ul style="list-style-type: none"> • Bread – ½ to 1 slice • Rice, pasta, potatoes – ¼ to ½ cup • Cooked cereal – ¼ to ½ cup • Ready-to-eat cereal – ¼ to ½ cup • Tortilla – ½ to 1 	<ul style="list-style-type: none"> • Bread – 1 slice • Rice, pasta, potatoes – ½ cup • Cooked cereal – ½ cup • Ready-to-eat cereal – ¾ to 1 cup • Tortilla – 1 	<ul style="list-style-type: none"> • Bread – 1 slice • Rice, pasta, potatoes – ½ cup • Cooked cereal – ½ cup • Ready-to-eat cereal – 1 cup • Tortilla – 1 	<ul style="list-style-type: none"> • Bread – 1 slice • Rice, pasta, potatoes – ½ cup • Cooked cereal – ½ cup • Ready-to-eat cereal – 1 cup • Tortilla – 1
Vegetables	<ul style="list-style-type: none"> • Cooked or pureed – 2 to 4 Tablespoons • Raw – few pieces, if child can chew well 	<ul style="list-style-type: none"> • Cooked or pureed – 3 to 4 Tablespoons • Raw – few pieces 	<ul style="list-style-type: none"> • Cooked or pureed – ½ cup • Raw – ½ to 1 cup 	<ul style="list-style-type: none"> • Cooked or pureed – ½ cup • Raw – ½ to 1 cup
Fruit	<ul style="list-style-type: none"> • Raw (apple, banana, etc.) – ½ to 1 small, if child can chew well • Canned – 2 to 4 Tablespoons • Juice – 3 to 4 ounces 	<ul style="list-style-type: none"> • Raw (apple, banana, etc.) ½ to 1 small, if child can chew well • Canned – 4 to 8 Tablespoons • Juice – 4 ounces 	<ul style="list-style-type: none"> • Raw (apple, banana, etc.) – 1 small • Canned – ¾ cup • Juice – 5 ounces 	<ul style="list-style-type: none"> • Raw (apple, banana, etc.) – 1 • Canned – ¾ cup • Juice – 6 ounces
Milk	<ul style="list-style-type: none"> • Milk, yogurt, pudding – 2 to 4 ounces • Cheese – ¾ ounce 	<ul style="list-style-type: none"> • Milk, yogurt, pudding – ½ to ¾ cup • Cheese – 1 ounce 	<ul style="list-style-type: none"> • Milk, yogurt, pudding – 1 cup • Cheese – 1 ½ ounces 	<ul style="list-style-type: none"> • Milk, yogurt, pudding – 1 cup • Cheese – 1 ½ ounces
Meat, Poultry, Fish, Other Protein	<ul style="list-style-type: none"> • Meat, poultry, fish – 1 to 2 ounces • Eggs – ½ to 1 • Peanut butter – 1 Tablespoon • Cooked dried beans – 4 to 5 Tablespoons 	<ul style="list-style-type: none"> • Meat, poultry, fish – 1 to 2 ounces • Eggs – 1 to 2 • Peanut butter – 2 Tablespoons • Cooked dried beans – 4 to 8 Tablespoons 	<ul style="list-style-type: none"> • Meat, poultry, fish – 2 ounces • Eggs – 2 • Peanut butter – 3 Tablespoons • Cooked dried beans – 1 cup 	<ul style="list-style-type: none"> • Meat, poultry, fish – 2 to 3 ounces • Eggs – 2 • Peanut butter – 4 Tablespoons • Cooked dried beans – 1 cup

MODULE 4: Fluid and Bowel Problems

LEARNING OBJECTIVES

After completing this module, you will have the skills and resources to:

- Understand normal bowel function and fluid status
- Elicit information about a child's fluid and bowel status
- Describe the potential effects of specific conditions, medications, and food patterns on fluid status and bowel function
- Identify intervention strategies for problems with fluid status and bowel function

RESOURCES

Fluid and Bowel Problems. Fluid and bowel problems. In: Isaacs JS, et al. *Children with Special Health Care Needs: A community pocket guide*. Dietetics in Developmental and Psychiatric Disorders and the Pediatric Nutrition Practice Group of The American Dietetic Association and Ross Products Division. 1997. This chapter describes normal bowel function, as well as some problems with fluid status and bowel functions that may occur among children with special needs. This publication is currently unavailable. A 2nd edition is under development.

Nutrition and Constipation. Ogata B. Nutrition and Constipation. *Nutrition Focus*. 1998. 13(3). This article describes some causes of constipation and some nutrition-related strategies for preventing constipation. To order, visit http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

Nutrition Concerns in Acute and Chronic Diarrhea. Katsh N. Nutrition concerns in acute and chronic diarrhea. *Nutrition Focus*. 2000. 15(6). This article includes a discussion of causes and treatments for chronic and acute diarrhea in infants and children. To order, visit http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

Constipation: Position Statement. Baker SS, Liptak GS, Colletti RB, et al. Constipation in infants and children: evaluation and treatment. A medical position statement of the North American Society for Pediatric Gastroenterology and Nutrition. *J Pediatr Gastroenterol Nutr* 1999; 29(5): 612-26. This position statement includes algorithms for evaluation and treatment of constipation. It is available on-line at: <http://www.naspgn.org/pdf/constipation.pdf>.

Serum b-carotene, retinal and a-tocopherol levels during mineral oil therapy for constipation. Clark JH et al. Serum b-carotene, retinal and a-tocopherol levels during mineral oil therapy for constipation. *AJDC*. 1987;141:1210-2.

The Management of Acute Gastroenteritis in Young Children: Practice Parameter. Provisional Committee on Quality Improvement, Subcommittee on Acute Gastroenteritis. Practice Parameter: the management of acute gastroenteritis in young children. *Pediatrics*. 97(3): 424-436. 1996. This article provides recommendation for the management of gastroenteritis in young children. Available online: <http://www.aap.org/policy/gastro.htm>.

Dietary Reference Intake for Macronutrients. Institute of Medicine. *Dietary Reference Intakes for Energy, Carbohydrate, Fiber, Fat, Fatty Acids, Cholesterol, Protein, and Amino Acids (Macronutrients)*. Food and Nutrition Board. Washington DC: National Academy Press, 1998. This report is available on-line. A hard copy can be ordered from <http://www.nap.edu/catalog/6015.html>.

MODULE 5: Integrating Community Services and Programs

LEARNING OBJECTIVES

After completing this module, you will have the skills and resources to:

- identify potential community service providers to help families put nutrition recommendations into practice
- incorporate nutrition therapy goals into the educational system for children with special needs
- describe other resources for families of children with special health care needs and describe some methods of evaluation of web-based information
- incorporate community resources into a nutrition care plan

RESOURCES IDENTIFIED IN MODULE

Medicaid - <http://cms.hhs.gov/medicaid/>

The Early and Periodic Screening, Diagnosis and Treatment program (EPSDT) - <http://cms.hhs.gov/medicaid/epsdt/>

The Supplemental Nutrition Program for Women, Infants, and Children (WIC) - <http://www.fns.usda.gov/wic/>

Title V/CSHCN Program - www.mchb.hrsa.gov/

Supplemental Security Income (SSI) - <http://www.ssa.gov/pubs/10026.html>

Head Start - <http://www2.acf.dhhs.gov/programs/hsb/>

Early Head Start - <http://www.ehsnrc.org/>

Food Stamp Program - <http://www.fns.usda.gov/fsp/>

Child and Adult Care Food Program (CACFP) – <http://www.fns.usda.gov/cnd/care/cacfp/cacfphome.htm> and <http://www.nal.usda.gov/childcare>

The Arc of America – <http://www.thearc.org>

The Center for Children with Special Needs – <http://www.chscn.org>

Family Village – <http://www.familyvillage.wisc.edu/index.html>



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<http://www.pacificwestmch.org>

Exceptional Parent magazine <http://www.eparent.com>

Family Voices <http://www.familyvoices.org>

The National Center for Children and Youth with Disabilities
<http://www.nichcy.org>

National Organization of Rare Diseases (NORD) <http://www.rarediseases.org>

ADDITIONAL RESOURCES

Community Services and Providers. Community services and providers. In: Isaacs JS, et al. *Children with Special Health Care Needs: A community pocket guide*. Dietetics in Developmental and Psychiatric Disorders and the Pediatric Nutrition Practice Group of The American Dietetic Association and Ross Products Division. 1997. This chapter describes some programs and resources that are available for children with special health care needs. This publication is currently unavailable. A 2nd edition is under development.

Bright Futures: Nutrition Resources. Appendix J: Nutrition resources. In: Story M, Holt K, Sofka D, eds. 2002. *Bright Futures in Practice: Nutrition* (2nd ed.). Arlington, VA: National Center for Education in Maternal and Child Health. This document lists general and federal nutrition resources as well as resources for specific nutrition issues and concerns. This publication is available online at <http://www.brightfutures.org> and print copies can also be ordered.

Accommodating Special Dietary Needs in the School. Marcelynas B, Brandis B. Accommodating special dietary needs in the school. In: Nardella M, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2001. This chapter describes the legislation that requires accommodations for special health care needs and presents some guidelines for implementation. To order, contact the Washington State Department of Health, Revenue Section, PO Box 1099, Olympia WA 98504 or visit the Washington State Nutrition for Children with Special Health Care Needs website: <http://depts.washington.edu/cshcnut>. The publication can also be downloaded from the WA DOH website: <http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>.

Nutrition Management of Handicapped and Chronically Ill School Age Children. Horsley JW, Allen E, White P. *Nutrition Management of Handicapped and Chronically Ill School Age Children-A Resource Manual for School Personnel, Families, and Health Professionals*. Virginia Department of Education. 1996. Resources to assist school personnel in planning nutritional services for

children with special health care needs and incorporating nutritional goals into IEP objectives.

Project Chance, A Guide to Feeding Young Children with Special Needs.

Project Chance, A Guide to Feeding Young Children with Special Needs. Arizona Department of Health Services. 1995. Designed to assist early childhood program staff and other caregivers in feeding and nourishing children with special needs. Available from the Office of Nutrition Services, Arizona Department of Health Services, 1740 W. Adams, Room 203, Phoenix AZ 85007. Also available on-line: <http://www.hs.state.az.us/phs/ocshcn/publications/prochance.htm>.

CARE: Nutrition for Kids. *CARE: Special Nutrition For Kids.* Department of Education, State of Alabama. 1995. A manual and instructional videotape for training Child Nutrition program managers about planning and preparing meals for children with special needs. Ordering information is available on-line: <http://www.olemiss.edu/depts/nfsmi/>.

Nutrition Issues Facing Children with Special Health Care Needs in Early Intervention Programs and at School. Horsley JW. Nutrition issues facing children with special health care needs in early intervention programs and at school. *Nutrition Focus.* 1994; 9(3). To order, visit http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

Accommodating Children with Special Dietary Needs in School Nutrition Programs. United States Department of Agriculture Food and Nutrition Service. *Accommodating Children with Special Dietary Needs in School Nutrition Programs: Guidance for school food service staff.* 2001. This document describes the mandated accommodations to school meal programs. Available on-line: http://www.fns.usda.gov/cnd/Guidance/special_dietary_needs.pdf.

Special Diet Needs. *Special Diet Needs.* North Carolina Nutrition Services Branch. A resource for families of children who need special dietary accommodations at school, this webpage includes guidelines for special meals, and information about requesting accommodations from the school system. http://www.nutritionnc.com/special/special_diet.htm.

Resources on Special Education, IEPs, IDEA, Inclusion and Section 504. *Resources on Special Education, IEPs, IDEA, Inclusion and Section 504.* Resources for families can be found on-line: <http://www.angelfire.com/ny/Debsimms/education.html#ideas>.

IDEA Regulations. IDEA 1997 Regulations website. This website includes the text of the 1997 IDEA (Individuals with Disabilities Education Act) Regulations and information about the legislation. <http://www.ed.gov/offices/OSERS/Policy/IDEA/regs.html>.



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<http://www.pacificwestmch.org>

Cost Considerations Article. Feucht S, Lucas B, Nardella M. Nutrition services for children with special health care needs – what are the cost considerations? *Nutrition Focus*. 1999; 14(6). This article describes the Cost Considerations document. To order, visit http://depts.washington.edu/chdd/ucedd/CO/co_NutriFocus.html.

Cost Considerations. *Cost Considerations: The benefits of nutrition services for a case series of children with special health care needs in Washington state.* Washington State Department of Health. 1999. This report highlights the results of the cost-benefit study described above. A copy of the report is available online at <http://www.ask.hrsa.gov> Item No. MCHK111.

MODULE 6: Putting It All Together...developing a family-centered plan

LEARNING OBJECTIVES

After completing this module, you will have the skills and resources to:

- Use growth, medical, and intake data to formulate a nutrition care plan
- Incorporate measurable outcomes for evaluation of the plan
- Include community services and programs in a nutrition care plan

RESOURCES

Developing a Plan

Providing Nutrition Services for Infants, Children and Adults with Developmental Disabilities and Special Health Care Needs: Position Paper.

Cloud HH, Posthauer ME. Providing nutrition services for infants, children, and adults with developmental disabilities and special health care needs. *J Am Diet Assoc.* 104:97-107. This position paper documents why nutrition services are essential and gives factors to consider when providing and planning nutrition services. It is available on-line to ADA members at:

http://www.eatright.org/Public/GovernmentAffairs/92_18463.cfm.

Nutrition in Comprehensive Program Planning for Persons with

Developmental Disabilities: Position Paper. Lucas BL, Blyler EM. Position of the American Dietetic Association: Nutrition in comprehensive program planning for persons with developmental disabilities. *J Am Diet Assoc* 97(2): 189-193. This position paper provides guidance regarding the provision of clinical nutrition services for persons with developmental disabilities and presents program planning recommendations. It is available on-line to ADA members at:

http://www.eatright.org/Public/GovernmentAffairs/92_adap0297b.cfm.

Pediatric Manual of Clinical Dietetics. Nevin-Follino N, ed. *Pediatric Manual of Clinical Dietetics, 2e.* American Dietetic Association. 1998. This diet manual provides practice guidance for the nutrition care of pediatric patients. The manual is available through ADA's on-line catalog:

http://www.eatright.org/Public/ProductCatalog/SearchableProducts/104_8444.cfm.

Family-Centered Care

Institute for Family-Centered Care. This non-profit organization is a resource for policy makers, administrators, program planners, direct service providers, educators, and family members. The website includes information about resources related to family-centered care, including publications and videos, newsletters, seminars, and presentations. The website also features a bulletin board to promote discussion about issues related to family-centered care.

<http://www.familycenteredcare.org/>

Family/Professional Collaboration. Bishop KK, Woll J, Arango P. *Family / Professional Collaboration*. Department of Social Work, University of Vermont. This 48-page document describes the seven principles of family/ professional partnerships. Available from the Available through the HRSA Information Center <http://www.ask.hrsa.gov> Inventory Code: MCHG017.

Family Voices. Family Voices works toward addressing the common challenges that all children with special health care needs face. Their advocacy efforts revolve around three basic principles that the organization believes should be part of health care reform: family-centered care, community-based services, and parent-professional collaboration. The site serves as a national clearinghouse for information and resources. <http://www.familyvoices.org>.

Family Village. This easy-to-navigate site describes itself as a global community on the Internet for families of persons who have disabilities. It has a wealth of information, resources, and web site connections for people with disabilities and their families and service providers. <http://familyvillage.wisc.edu>.