eat right. Academy of Nutrition and Dietetics

POCKET GUIDE TO

Children With Special Health Care and Nutritional Needs

SECOND EDITION

Behavioral Health Nutrition Dietetic Practice Group and Pediatric Nutrition Practice Group

Editors

Wendy Wittenbrook
MA, RD, CSP, LD, FAND

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Frequently Used Terms and Abbreviations

AAP	American Academy of Pediatrics
ABA	applied behavioral analysis
ADL	activities of daily living
ARFID	Avoidant/Restrictive Food Intake Disorder
ASD	autism spectrum disorder
ASPEN	American Society for Parenteral and Enteral Nutrition
BIA	bioelectrical impedance analysis
BMI	body mass index
BTF	blenderized tube feedings

CAM	complementary and alternative medicine
CDC	Centers for Disease Control and Prevention
CF	cystic fibrosis
CP	cerebral palsy
CSHCN	children with special health care needs
DLW	doubly labeled water
DNR	do not resuscitate
DRI	Dietary Reference Intake
DXA	dual-energy x-ray absorptiometry
EER	estimated energy requirement
EI	early intervention
EN	enteral nutrition
EPSDT	early periodic screening, diagnosis, and treatment
FARE	Food Allergy Research and Education
FDA	US Food and Drug Administration

FERPA	Family Educational Rights and Privacy Act
FFM	fat-free mass
FODMAPs	fermentable oligosaccharides, disaccharides, monosaccharides, and polyols
G-tube	gastrostomy tube
GERD	gastroesophageal reflux disease
GI	gastrointestinal
HIPAA	Health Insurance Portability and Accountability Act
IBCLC	International Board Certified Lactation Consultant
IDEA	Individual With Disabilities Education Act of 1997
IDDSI	International Dysphagia Diet Standardisation Initiative
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan
IgA	immunoglobulin A
IgE	immunoglobulin E

IHS	Indian Health Services
J-tube	jejunostomy
LBW	low birth weight
MCT	medium-chain triglycerides
MBSS	modified barium swallow study
MNT	medical nutrition therapy
MSW	medical social worker
MUAC	mid-upper arm circumference
NCCIH	National Institute of Health, National Center for Complementary Integrative Health
NFPE	nutrition-focused physical examination
NG	nasogastric
NI	neurological impairment
NICU	neonatal intensive care unit
NSBP	National School Breakfast Program
NSLP	National School Lunch Program

OT	occupational therapist
PA	physical activity coefficient
PKU	phenylketonuria
PN	parenteral nutrition
POST	Physician Orders for Scope of Treatment
PPE	personal protective equipment
PT	physical therapist
PWS	Prader-Willi syndrome
RAST	radioallergosorbent test
RDA	Recommended Dietary Allowance
REE	resting energy expenditure
RDN	registered dietitian nutritionist
RN	registered nurse
SCHIP	State Children's Health Insurance Program
SLP	speech-language pathologist
SNAP	Supplemental Nutrition Assistance Program
SSI	Supplemental Security Income

SSRI	selective serotonin reuptake inhibitor
TBI	traumatic brain injury
TEE	total energy expenditure
TRICARE	health care program of the US Department of Defense Military Health System (formerly Civilian Health and Medical Program of the Uniformed Services [CHAMPUS])
TSF	triceps skin fold
UL	Tolerable Upper Intake Level
USDA	United States Department of Agriculture
VFSS	videofluoroscopic swallow study
VLBW	very low birth weight
WHO	World Health Organization
WIC	Special Supplemental Nutrition Program for Women, Infants, and Children

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Introduction

Almost 20% of American children under 18 years of age have some type of special health care need.[1] The special health care needs result from a variety of chronic illnesses or conditions. Many of these children are at nutritional risk resulting from altered metabolism, gastrointestinal dysfunction or malabsorption, medication-nutrient interactions, developmental issues, and behavioral issues related to their chronic condition. Inadequate nutrition results in poor growth and can compound many of the illness-related, developmental, or behavioral issues these children already face.

Since the publication of the 2012 edition of the *Pocket Guide to Children With Special Health Care and Nutritional Needs*, the Academy of Nutrition and Dietetics and the American Society for Parenteral and Enteral Nutrition published a consensus statement and indicators to identify and document pediatric malnutrition.[2,3] This second edition includes the updated information on pediatric malnutrition to help guide the practitioner to more consistently use these indicators. At the time of publication, the Academy of Nutrition and Dietetics is conducting

a study of the Malnutrition Clinical Characteristics with the aim of validating the indicators. Additionally, the study will look at nutrition-focused physical exam (NFPE) parameters as indicators.

NFPE has become part of the guidelines for training new dietitians and is part of a complete nutrition assessment according to the Nutrition Care Process from the Academy of Nutrition and Dietetics. As a result, a new chapter was added to this edition of the pocket guide. Chapter 2 reviews the examination process specific to the neurologically impaired child. The editors felt that basic NFPE is covered during internships and workshops and in nutrition textbooks and manuals. Since this is a pocket guide, we wanted to specifically address some of the questions that practitioners have related to the neurologically impaired child.

Improvements in medical and nutrition care of children with special health care needs have increased life expectancy and quality of life for these children. This means that there is a large population of children with special health care needs that will need to transition to adult health care. There is literature reviewing the process overall but very little literature addresses the transition of nutrition support services. Because of the importance of a successful transition from pediatric to adult health care, the editors added Chapter 7. Our hope is that nutrition professionals will become more involved with this process and help these children and their families successfully transition into adult health care.

The *Academy of Nutrition and Dietetics Pocket Guide to Children With Special Health Care and Nutritional Needs* is designed as an easy-to-access resource, and so it does not provide comprehensive information on the topics addressed. The intent is to provide a quick, practical reference for practitioners working with children with special nutritional needs. All of the chapters have been updated, and with the addition of malnutrition guidelines, NFPE, and transitioning of care, we hope to inspire practitioners to advance their practice and dive deeper into the topics for which they are most passionate.

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CHAPTER 1

Assessment of Growth

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Growth typically follows a predictable course. Growth potential is determined by genetics and is also influenced by biological and environmental factors that can include disease, diet, and social and environmental circumstances. Early identification of growth problems is important because timely therapeutic interventions are important to support a child's general health and functional abilities by promoting adequate and appropriate growth. Growth assessment is based on changes in anthropometric measurements and body composition as compared to a norm. Accurate and consistent measurements are key not only for a complete nutrition assessment but also for early diagnosis of malnutrition. There can be both nutritional and nonnutritional reasons for different growth patterns. It is important

to set realistic growth expectations for each individual child.

Screening and Assessment Tools

The terms *screening* and *assessment* are often used interchangeably, but they are fundamentally different. The goal of nutritional screening is to identify patients who are already undernourished or at risk to become undernourished, whereas the goal of nutrition assessment is to describe the current nutritional state of patients. Children with special health care needs (CSHCN) should be screened for malnutrition routinely in all health care settings.[1] Successful screening should result in the early identification of CSHCN who will benefit from in-depth nutrition assessment and intervention. Assessment of nutritional status should also occur routinely in CSHCN, with a focus on longitudinal tracking of anthropometric and growth-related data points. The goal is to prevent the negative consequences associated with malnutrition, such as increased hospital length of stay, disease progression, and increased health care costs.[1-3]

Multiple tools have been created to assist in the screening and assessment of pediatric malnutrition.[4-10] A major limitation in the use of any of these tools in CSHCN is the lack of validation in this population as a whole, but particularly CSHCN in the outpatient setting. The Subjective Global Nutritional Assessment (SGNA)[8]—a nutrition assessment tool adapted in 2007 for pediatric

assessment—has been validated in multiple pediatric populations,[6,11-14] including children with cerebral palsy.[15] However, one criticism of the SGNA is the length of time it takes to administer.[16] This drawback can be overcome with practice and as skills advance.

Obtaining Accurate Measurements

In the population of CSHCN, measurement errors are frequent. Length and height measurements can be particularly challenging because of the physical limitations of the child. Additionally, measuring using improper techniques or the wrong equipment renders the measurement useless. Use of standard measurement techniques may not be possible in children with contractures, scoliosis, or spastic movements. When accurate measurements are not possible using the standard methods, alternate methods are available. Potential errors when weighing the child can occur with the use of different scales in different settings; when subtracting the weight of a person holding the child; when converting between pounds and kilograms; and with incorrect technique, malfunctioning equipment, or lack of calibration.[17] When significant unexpected changes are seen, repeating measurements is an important practice. Above all, clinical judgment should be used.

Length, Height, and Alternate Measurements

A recumbent length is measured on children less than 2 years of age. A calibrated solid length board or infantometer is used; proper technique requires two clinicians or a parent and a clinician. The child is positioned on his back with his head at the stationary end of the board with the first clinician or parent holding the head in position. The second clinician straightens the legs and pulls the repositionable piece of the board toward the bottom of the child's feet so that the heels are touching the board and toes are pointing toward the ceiling.[18]

When the child is 2 years of age and older and can stand, then a standing height is the preferred measurement. A standing height is measured using a stadiometer. The child is instructed to stand against the wall where the stadiometer is fixed, facing away from the wall with heels, buttocks, shoulders, and back of the head touching the wall. The top of the stadiometer is positioned on the top of the head and the measurement noted.[18]

It may be difficult to obtain accurate measurements in children with contractures, scoliosis, or impaired muscle tone. Alternate methods for assessing height include segmental length, knee height, upper arm length, ulnar length, or tibial length. If standing height cannot be obtained, segmental length is the preferred method, taking the sum of individual segmental recumbent lengths as a proxy for standing height.[19]

Kihara and colleagues found that tibial length was a reliable proxy measure for height in 50 children with moderate-to-severe cerebral palsy with and without joint contractures or scoliosis.[20] Although repeatability for tibial measurements is usually high, there is fair to poor agreement between the estimated height and the actual height. The difference is more significant as height increases.[21] Tibial length is measured using a flexible tape measure by a trained clinician. The measurement is taken on the left leg if possible with the left ankle positioned on the right knee. The tibia is measured from the ankle to just below the knee.[18] The estimated height is calculated:

$$\text{Height in centimeters} = (3.26 \times \text{tibial length in centimeters}) + 30.822$$

Arm span or total arm length can be used to estimate height for children who cannot stand.[23] It has limited use in CSHCN who have upper body contractures or who are unable to sit with their back against the wall. To measure an arm span, two clinicians are needed. The patient is standing or sitting with back against a wall, arms raised at a 90-degree angle, palms front, and a clinician at each side. The measurement is taken from the tip of one middle finger to the tip of the other.[18]

Reference standards for upper arm and lower leg length are available for children older than 2 years with cerebral palsy.[24] Crown-rump length or sitting height

measurement is also useful for longitudinal monitoring of children with contractures of the lower body. This can show if a child is growing over time in the upper body, but these measurements will not correlate directly with height or length. It is important to use the same techniques for estimating anthropometrics, especially height, at each visit and document the measurement method used for other providers.

Mid-Upper Arm Circumference

Anthropometric measurements, particularly for height, may be inaccurate or missing in CSHCN for many reasons. Without height, it becomes impossible to utilize most or all of the nutritional status indicators noted in Table 1.1 (see page 9). Mid-upper arm circumference (MUAC) can be used as an independent anthropometric indicator of nutritional status. It is recommended that nutritional assessments of all pediatric patients include MUAC.[1] MUAC should be performed by a trained clinician. It is relatively quick and simple to perform in practice, and the only equipment required is a tape measure. The midpoint of the arm is determined with the patient sitting or standing and positioning the arm at the side by the rib cage with the arm bent at the elbow at a 90-degree angle. The back of the upper arm is measured between the acromion process and the lower tip of the elbow. The midpoint is calculated and marked. The circumference is measured at the midpoint with the arm straight and relaxed at the side.[18]

Growth Charts

Centers for Disease Control and Prevention Growth Charts/World Health Organization Growth Standards

The Centers for Disease Control and Prevention (CDC) growth charts and World Health Organization (WHO) growth standards should be used only with careful interpretation, as CSHCN were not included in the reference population. The Maternal and Child Health Bureau provides an online training module that addresses the use of CDC growth charts for CSHCN (http://depts.washington.edu/growth/cshcn/text/intro.htm).

The CDC recommends that WHO growth standards be used to monitor growth for infants and children in the United States from birth to 2 years of age. After 40 weeks' gestation, preterm infants should be plotted on WHO charts using corrected age until they reach a chronological age of 24 months. WHO charts are gender and age specific and can be used for children with a birth weight more than 1,500 g and born at or above 38 weeks' gestation or corrected to above 40 weeks' gestation. WHO growth charts allow for assessment of growth indexes of weight-for-age, length-for-age, head circumference-for-age, and weight-for-length. CDC growth charts are used for children and adolescents between 2 and 20 years of age. CDC growth

charts allow for growth indexes' assessment of weight-for-age, height-for-age, and body mass index (BMI)-for-age. CDC growth charts and WHO growth standards can be downloaded from the CDC website (www.cdc.gov/growthcharts). Table 1.1 provides guidelines for interpretation of growth in CSHCN using CDC charts.[25]

The use of the Olsen or more recent Fenton growth charts is most appropriate when an infant is premature. In 2013, the Fenton growth chart for preterm infants was revised to accommodate WHO growth standards and reflect actual age instead of completed weeks of gestation in order to improve preterm infant growth monitoring.[26] In 2010, Olsen and colleagues published data collected from 33 US states and 248 hospitals on infants 22 to 42 weeks of age.[27] The preferred growth chart used to measure preterm infants varies by institution or clinician. It is important for an institution/clinician to use the same chart consistently to plot infant growth.

z Scores

z scores for length/height-for-age, weight-for-age, weight-for-length, BMI, or MUAC provide an accurate evaluation of discrete changes from one measure to another. Percentile tables typically describe ranges, and consequently detection of movement within the range or when outside of the range is difficult to describe. The *z* score denotes standard deviation units from the mean and is more precise than percentile ranges. A positive *z* score means that the value lies above the mean, and a negative *z* score corresponds to a value that lies below the

mean. *z* Scores allow for earlier identification of malnutrition vs tracking through growth percentiles alone, as well as provide data to monitor growth in children who are well outside of the normal range. Programs available online to calculate *z* scores can be found on the CDC Epi Info website (www.cdc.gov/epiinfo) and Pedi Tools (www.peditools.org).

TABLE 1.1 Nutritional Status Indicators Using Centers for Disease Control and Prevention Growth Charts[25]

Anthropometric index	Percentile cut-off value (nutritional status indicator)	Interpretation for child with special health care needs[a]
Body mass index (BMI)-for-age or weight-for-length	> 95th (Obesity) > 85th and < 95th (Overweight)	Common in Down syndrome or conditions that cause skeletal deformities, such as spina bifida and scoliosis Common in conditions that limit ambulatory abilities or decrease energy utilization, such as mechanical ventilation
BMI-for-age or weight-for-length	< 5th (Underweight)	Common in conditions that limit muscle mass, such as spastic quadriplegia cerebral palsy Common in feeding disorders Common in conditions that affect absorption and metabolism

Continued on next page

TABLE 1.1 Nutritional Status Indicators Using Centers for Disease Control and Prevention Growth Charts[25] (cont.)

Anthropometric index	Percentile cut-off value (nutritional status indicator)	Interpretation for child with special health care needs[a]
Height/ length-for-age	> 95th (Tall for age)	Unusual, but characteristic of rare genetic disorders Obese patients may prematurely go through the adolescent growth spurt and be tall for age while younger
	< 5th (Short for age)	Usually seen in neurologic disorders; microcephaly May be related to prenatal factors or genetic disorder May also be nutrition related in chronic severe malnutrition
Head circumference-for-age	> 95th (Macrocephaly) < 5th (Microcephaly)	Developmental delays

[a] Interpretation related to children with special health care needs is based on clinical practice.

Specialized Growth Charts

Many CSHCN have diagnoses for which there are no standardized growth charts; however, specialized charts are available describing the growth of infants

APPENDIX A

Resources

Books, Manuals, Modules, and Newsletters on Special Health Care Needs

***Pediatric Swallowing and Feeding: Assessment and Management*, 3rd Edition**
Arvedson JC, Brodsky L, Lefton-Greif MA. Plural Publishing; 2019.

Handbook for Children with Special Food and Nutrition Needs
Cloud HH, Bomba A, Carithers T, Tidwell D. National Food Service Management Institute; 2006. www.kysna.org/assets/docs/20080213015556.pdf

***The ASPEN Pediatric Nutrition Support Core Curriculum*, 2nd Edition**
www.eatrightSTORE.org
Corkins MR, ed. American Society for Parenteral and Enteral Nutrition; 2015.

***Pediatric Nutrition in Chronic Diseases and Developmental Disorders*, 3rd Edition**
Ekvall SW, Ekvall VK. Oxford University Press; 2017.

Interdisciplinary Clinical Assessment of Young Children With Developmental Disabilities
Guralnick MJ, ed. Brookes Publishing; 2000.

***The Down Syndrome Nutrition Handbook—A Guide to Promoting Healthy Lifestyles*, 2nd Edition**
Medlen JG. Phronesis Publishing; 2006.
www.DownSyndromeNutrition.com

Nutrition Focus for Children with Special Health Care Needs
http://depts.washington.edu/cshcnnut/resources/nutfocus.html
Newsletter published six times annually, with each issue focused on a specific disorder or condition

***Nutrition for Children with Special Health Care Needs* (web-based modules)**
Ogata B, et al. Pacific West MCH Distance Learning Network.
http://depts.washington.edu/pwdlearn/web/index.php

***Pocket Guide to Neonatal Nutrition*, 2nd Edition**
Pediatric Nutrition Practice Group, Academy of Nutrition and Dietetics. Academy of Nutrition and Dietetics; 2016.
www.eatrightSTORE.org

***Infant Feedings: Guidelines for the Preparation of Human Milk and Formula in Health Care Facilities*, 3rd Edition**
Pediatric Nutrition Practice Group, Academy of Nutrition and Dietetics. Academy of Nutrition and Dietetics; 2018.
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***Nutrition Interventions for Children with Special Health Care Needs*, 3rd Edition**
Yang Y, Lucas B, Feucht S, eds. Washington State Department of Health; 2010. www.doh.wa.gov/Portals/1/Documents/8100/961-158-CSHCN-NI-en-L.pdf

Indian Health Services, US Department of Health and Human Services
www.ihs.gov

Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services Title V Maternal and Child Health Services Block Grant Program
http://mchb.hrsa.gov/programs/titlevgrants/index.html

Medicaid Program, Centers for Medicare & Medicaid Services, US Department of Health and Human Services
www.cms.gov/home/medicaid.asp

National Down Syndrome Society
www.ndss.org
A comprehensive resource for Down syndrome.

National Information Center for Children and Youth with Disabilities
www.parentcenterhub.org
Targeted mainly toward educational programs.

National Organization for Rare Diseases (NORD)
https://rarediseases.org

State Children's Health Insurance Program (SCHIP)
www.cms.gov/home/chip.asp

Supplemental Security Income (SSI), Social Security Administration
www.ssa.gov/pubs/10026.html

APPENDIX B

Glossary

504 Accommodation Plan Planning document used in schools for children who require health-related services (including modifications to diets for dysphagia and food allergies) but who are not enrolled in a special education program; mandated by the Rehabilitation Act of 1973.

achondroplasia An inherited congenital disorder that is characterized by short stature, short limbs, normal trunk, large head, prominent forehead, and low nasal bridge.

Americans with Disabilities Act of 1990 Federal legislation enacted to protect individuals with disabilities from discrimination.

anal stenosis A condition in which the anus is narrowed.

ankyloglossia (Tongue-tie) is a condition present at birth that restricts the tongue's range of motion; an unusually short, thick, or tight band of tissue (lingual frenulum) tethers the bottom of the tongue's tip to the floor of the mouth.

anthropometric Pertaining to the science of measuring the body, including height, length, weight, and the size of other body parts.

anticonvulsant Medication used to prevent or control the occurrence or severity of seizures; medication-nutrient interactions can affect metabolism of vitamins D, B6, B12, folic acid, and carnitine.

Apert syndrome A genetic disorder characterized by the premature fusion of certain skull bones (craniosynostosis).

apnea Cessation of breathing for a time; a sign of respiratory distress of multifactorial etiology, including prematurity and feeding problems in children with special health care needs.

arm span The distance between a child's extended right and left middle fingers, measured across the back; sometimes used to estimate height.

aspiration The ingestion of foreign material into the lungs, including food, liquid, or stomach contents; clinically significant aspiration requires consideration of non-oral feeding or surgery to protect the airway.

ataxia Imbalance or lack of coordination of voluntary and involuntary movements; seen in neurological disorders (eg, cerebral palsy).

athetoid/athetosis Condition of ceaseless, involuntary muscle movements; a type of cerebral palsy; can result in increased energy needs.

autism spectrum disorders (ASD) A neurodevelopmental disorder that is characterized by communication problems, restricted interests, impaired social interactions, and ritualistic behaviors.

body mass index (BMI) An indicator of weight and height proportionality used in nutrition screening (BMI in 85th to 95th percentile indicates overweight; BMI >95th percentile indicates obesity; BMI <5th percentile indicates underweight). BMI = weight (kg)/height $(m)^2$.

bolus Term used in enteral nutrition support for a feeding administered in a short time frame to stimulate a meal.

bronchopulmonary dysplasia A chronic lung disorder; most commonly seen in children born prematurely, with low birth weight, or those requiring prolonged mechanical ventilation; nutritional consequences can include feeding difficulties, slow growth, and increased energy needs.

bruxism Excessive teeth grinding or jaw clenching. It is an oral parafunctional activity; ie, it is unrelated to normal function such as eating or talking.

calipers An instrument with two hinged jaws used for measuring the thickness or diameter of an object.

catch-up growth Rate of growth that is faster than expected, seen when a child who has experienced stunted growth due to a nutritional insult receives adequate energy and protein.

celiac disease Autoimmune disorder that can occur in genetically predisposed people where the ingestion of gluten leads to damage in the small intestine.

cerebral palsy (CP) A nonprogressive motor nerve disorder of the central nervous system; a group of disorders that affect movement and muscle tone or posture. Results in muscle coordination difficulties. Different parts of the body are affected.

CHARGE A congenital condition (present from birth) that affects many areas of the body. CHARGE stands for coloboma, heart defect, atresia choanae (also known as choanal atresia), restricted growth and development, genital abnormality, and ear abnormality.

Children With Special Health Care Needs (CSHCN) program Federal- (Title V) and state-funded program located in state health departments; promotes and coordinates services for children who have serious physical, behavioral, or emotional conditions that require health and related services beyond those generally required by children.

chronic lung disease of infancy (CLD) A suggested term to describe infants who continue to have a significant pulmonary dysfunction at 36 weeks' gestational age.

chronic renal failure (CRF) Less than 25% renal function; may be due to congenital anatomical defects, inherited disease, untreated kidney infections, physical trauma, or exposure to nephrotoxic chemicals.

chronic renal insufficiency (CRI) Less than 50% renal function; a progressive disorder that can lead to chronic renal failure.

cleft lip and cleft palate Conditions that occur when tissues that usually form the lip or the roof of the mouth fail to grow together, creating a gap in the lip or a hole in the roof of the mouth; may be an isolated condition or may be associated with other syndromes.

***Clostridium difficile* (*C. diff*)** A bacterium that can cause symptoms ranging from diarrhea to life-threatening inflammation of the colon.

complementary and alternative medicine (CAM) Health care and medical practices that are not currently an integral part of conventional medicine but are used in conjunction with conventional medicine.

congenital heart disease A problem with the structure of the heart that is present at birth, involving one or more defects in the walls of the heart, the valves of the heart, arteries near the heart, or veins near the heart.

contracture Static muscle shortening resulting from tonic spasm or fibrosis; frequently seen in individuals with cerebral palsy.

Cornelia de Lange A genetic disorder that can lead to severe developmental anomalies, typically resulting in short stature, moderate to severe intellectual disability, limb differences, prominent facial features (including thin eyebrows that meet at midline and low set ears), in addition to other system abnormalities.

corrected age Age from birth, corrected for prematurity; 40 weeks minus gestational age at birth (eg, an infant born at 30 weeks' gestation has a corrected age of 2 weeks at 12 weeks after birth).

Crohn's disease an inflammatory bowel disease that causes inflammation of the digestive tract, which can lead to abdominal pain, severe diarrhea, fatigue, weight loss, and malnutrition.

crown-rump length Length between a child's head and buttocks; sometimes used as an estimation of length. The child is measured on the length board with legs at a 90-degree angle, and the footboard is brought up against the buttocks to obtain the measurement.

cystic fibrosis (CF) An inherited disease that affects the lungs and digestive system; the body produces thick and sticky mucus that can clog the lungs and obstruct the pancreas.

diaphragmatic hernia Protrusion of part of the stomach upwards through an abnormal opening between the thoracic and abdominal cavities; associated with respiratory, cardiac, and gastrointestinal problems.

Dietary Reference Intakes (DRIs) Generic term for a set of nutrient reference values; includes Estimated Average Requirement (EAR), Recommended Dietary Allowance (RDA), Adequate Intake (AI), Tolerable Upper Intake Level (UL), and Estimated Energy Requirement (EER).

dysphagia Difficulty in swallowing.

Early Head Start Expansion of the Head Start program to serve low-income pregnant women, infants, and children up to age 3 years; program components include education; social services; meals and snacks; and health, nutrition, and dental screening and education.

early intervention services Community-based, comprehensive therapeutic and educational services for infants and children up to 3 years of age with developmental delays; established by Part H of the federal Individuals With Disabilities Education Act (IDEA) of 1986 (now Part C).

Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Medicaid program for individuals under 22 years of age; provides medical and dental services; can often provide nutrition-related specialty services, depending on state restrictions.

Ehlers-Danlos syndrome A group of inherited disorders that affect the connective tissues, primarily skin, joints, and blood vessel walls, which provide strength and elasticity to the underlying structures in the body.

encopresis Fecal incontinence not due to organic defect or illness.

eosinophilic esophagitis (EoE) Also spelled eosinophilic oesophagitis; also known as allergic esophagitis. An allergic inflammatory condition of the esophagus that involves eosinophils, a type of white blood cell. Symptoms are swallowing difficulty, food impaction, vomiting and heartburn.

Estimated Energy Requirement (EER) Dietary reference intakes (DRI) for energy; calculated using a physical activity coefficient (PA).

failure to thrive (FTT) Refers to slowed rate of growth, usually describes weight loss, decreased rate of weight gain, or decreased linear growth; also called undernutrition, delayed growth, growth faltering, and failure to grow.

Food Protein–Induced Enterocolitis Syndrome (FPIES) A type of food allergy affecting the gastrointestinal tract. Classic symptoms of FPIES include profound vomiting, diarrhea, and dehydration. These symptoms can lead to severe lethargy, change in body temperature, and blood pressure.

fragile X A genetic disorder that often includes mild to moderate intellectual disability. Physical features may include a long and narrow face, large ears, flexible fingers, and large testicles.

Freeman-Sheldon syndrome A rare inherited disorder present from birth, characterized by joint deformities (contractures) that restrict movement in the hands and feet and abnormalities of the head and face.

fundoplication Surgical procedure that wraps the fundus of the stomach around the lower esophageal sphincter; used for treatment of severe/chronic gastroesophageal reflux disease (GERD); sometimes done during gastrostomy tube placement.

gag reflex A normal reflex triggered by touching the soft palate or back of the throat, which raises the palate, retracts the tongue, and contracts the throat muscles; protects the airway from a bolus of food or liquid.

galactagogue Substance that is ingested (foods, herbs, medications) to increase breast milk supply (induces lactation).

gastroesophageal reflux disease (GERD) Regurgitation of stomach contents upward through the lower esophageal sphincter into the esophagus, where they can be aspirated; results in uncomfortable, burning sensation; common cause of feeding and eating problems in infants and children with neuromuscular disabilities.

gastroschisis A birth defect when there is incomplete closure of the abdominal wall, and the bowel pushes through the opening; other organs, such as the stomach and liver, can also be found outside the body.

gastrostomy tube A feeding tube surgically placed through an opening from the abdomen to the stomach; tube can also be placed endoscopically.

glycogen storage diseases Deficiency of enzymes that regulate the synthesis or degradation of glycogen; results in hypoglycemia, which can be life-threatening; treatment can include nocturnal drip feedings of a carbohydrate-containing solution or raw cornstarch therapy.

Goldenhar syndrome A rare congenital defect characterized by incomplete development of the ear, nose, soft palate, lip, and mandible.

granulation tissue Connective tissue that forms on the surface of a wound, ulcer, or inflamed tissue surface.

Head Start Federally funded preschool program for children ages 3 to 5 years from low-income families; includes children with special health care needs; program components include parent education, meals and snacks, health, nutrition, dental screening, and education.

height-age equivalent Age at which current length or height would fall at the 50th percentile on the length-for-age or height-for-age growth chart.

***Helicobacter pylori* (*H. pylori*)** A type of bacteria that can enter the body and live in the digestive tract; after many years, ulcers can form in the lining of the stomach of the upper part of the small intestine; can lead to stomach cancer for some people.

Hirschsprung disease Congenital absence of nerves in the smooth muscle wall of the colon, resulting in buildup of feces and widening of the bowel (megacolon).

hydrocephalus A congenital or acquired condition that results in accumulation of cerebrospinal fluid within the skull; characterized by enlarged head, prominent forehead, cognitive difficulties, and seizures. A mechanical shunt may be placed to drain the cerebrospinal fluid; a ventriculoperitoneal shunt is most commonly used.

hypersensitivity Exaggerated response by the body to a stimulus, such as touch, taste, or smell; in feeding problems, hypersensitivity includes adverse reaction or refusal to have mouth touched or teeth brushed, gagging or negative reaction to food in mouth, and tactile defensiveness.

hypertonia Increased muscle tone; facial hypertonia may result in oral-motor feeding difficulties, such as bite reflexes and retracted upper lip.

hypotonia Diminished muscle tone; can result in poor suck and feeding difficulties.

Indian Health Services Federal program that provides health services to Native Americans.

Individualized Education Program (IEP) Planning Document Required For Special Education Services In Public Schools Serving Children Older Than 3 Years; Outlines Specific Goals, Activities, And Timelines.

Individualized Family Service Plan (IFSP) Planning document required for services for children from birth to 3 years of age enrolled in early intervention services; includes specific goals, activities, and timelines.

Individual With Disabilities Education Act of 1997 (IDEA) Federal education legislation; Part C includes early intervention services for children with special health care needs.

Integrative Medicine A holistic, patient-focused approach to health care and wellness that focuses on treating the whole person (including mental, emotional, functional, spiritual, community, and social) and emphasizes well-coordinated care among providers.

International Dysphagia Diet Standardisation Initiative (IDDSI) Standardized terminology to describe food textures and thickness of drinks.

Intraventricular hemorrhage (IVH) Graded 1 (mild) to 4 (major); in premature infants, may be associated with subsequent neurological damage and developmental disability.

jaw grading Ability to control the degree of movement of the lower jaw; a feeding skill important in accepting food from a spoon and in biting and chewing.

jaw retraction Involuntary movement that pulls the jaw backward, making it difficult to open the mouth voluntarily; a common oral-motor feeding problem that interferes with the ability to handle food textures.

low birth weight (LBW) Used to describe a newborn weighing less than 2,500 g (5.5 lb) and less than 38 weeks gestation.

macrocephaly Excessively large head size.

Marfan syndrome Congenital disorder of the connective tissue characterized by excessive length of the fingers and toes; can lead to defects in the heart, blood vessels, eyes, bones, and joints.

Medicaid Federal program that provides health coverage for eligible low-income children and individuals with disabilities. Medicaid is administered by states, according to federal requirements; and funded jointly by states and the federal government.

medium-chain triglycerides (MCT) Triglycerides with 8 to 10 carbon atoms; they do not require bile for digestion and are easier to digest.

microcephaly Small head size in relation to age and other growth parameters; may reflect inadequate brain growth; common feature of neurological damage before or immediately after birth.

micrognathia A condition in which the jaw is undersized and may interfere with feeding and breathing; a symptom of a variety of craniofacial conditions; sometimes called mandibular hypoplasia.

modified barium swallow (MBSS) A radiologic study of the oral and pharyngeal cavities to evaluate the swallowing mechanism; foods and liquids are mixed with barium and the study is recorded for assessment and review; also called videofluoroscopic swallowing study (VFSS).

munching Oral-motor feeding developmental stage characterized by up-and-down movement of the jaw; occurs before development of rotary chewing.

myelomeningocele. See spina bifida.

myotonic dystrophy An inherited autosomal dominant form of muscular dystrophy that occurs in adults; characterized by progressive muscle weakness, wasting, and myotonia.

nasogastric feeding A form of enteral nutrition support; the feeding tube goes from the nose into the stomach; usually used temporarily (eg, less than 3 months).

National School Breakfast and Lunch Program School program in which children receive a balanced morning and midday meal; sponsored by the US Department of Argiculture's Child Nutrition Program.

necrotizing enterocolitis Inflammatory bowel disorder that occurs primarily in premature or low birth weight (LBW) infants; the wall of the intestine is invaded by bacteria, resulting in local infection and inflammation; resulting in necrosis, which can lead to perforation of the intestine.

Nellhaus chart Standard reference for head circumference in infants and children from birth to age 18 years.

Noonan syndrome A genetic disorder that causes multiple congenital abnormalities; characteristic features include failure to thrive, feeding difficulties, short stature, webbing of the neck, intellectual disability, and craniofacial features (wide mouth, protruding upper lip).

obstipation Constipation resulting in accumulation of feces with development of colon distention; leads to fecal impaction.

obstructive lesions Conditions where a normal body passage is partly or completely obstructed; examples of those affecting eating and nutrition include pyloric stenosis, tracheoesophageal fistula, duodenal atresia.

palmar grasp Hand movement in which the palm rather than the fingertips make contact with an object for grasping; developmental stage that is an important precursor to self-feeding.

phasic bite reflex Opening and closing of the jaw that occurs when the gums and teeth are stimulated.

phenylketonuria (PKU) An autosomal recessive inherited amino acid disorder; marked by the deficiency of the enzyme that converts phenylalanine to tyrosine; accumulation of phenylalanine in the blood can lead to intellectual disability and other neurological problems; identified in newborn screening; treatment includes a special diet with medical foods.

physical activity coefficient (PA) Coefficient used to determine estimated energy requirements (EER).

pica A psychological disorder characterized by intake of substances that are largely nonnutritive, such as ice.

Pierre-Robin sequence A genetic disorder that causes multiple congenital abnormalities; characterized by small lower jaw, airway obstruction caused by a tongue that is placed further back than normal, cleft palate, or other malformations; results in respiratory and feeding problems; also called Robin syndrome.

pincer grasp Refined, mature hand movement in which the thumb and index finger are used to grasp a small object; a developmental stage that is an important skill in self-feeding.

positioning Physical management of posture and body alignment to support daily living skills such as standing and eating.

postictal Altered state of consciousness after an epileptic seizure.

Prader-Willi syndrome (PWS) Genetic disorder of chromosome 15 marked by hypotonia, short stature, hyperphagia, cognitive impairment, and developmental disabilities; characterized by poor feeding due to hypotonia in infancy, and after infancy, hyperphagia and inability to tell when full leads to excessive weight gain when not carefully managed, excessive weight gain in children and adults.

preterm Term used to describe an infant who is born prematurely at less than 38 weeks' gestation.

recognized medical authority Term in federal regulations pertaining to Child Nutrition Programs that refers to a physician, physician's assistant, registered nurse, nurse practitioner, registered dietitian nutritionist, or other specialist identified by the state agency (eg, Department of Education).

Recommended Dietary Allowance (RDA) The intake that meets the nutrient needs of almost all (97%-98%) of individuals in a group.

retrognathia (or retrognathism) is a type of malocclusion which refers to an abnormal posterior positioning of the maxilla or mandible, particularly the mandible, relative to the facial skeleton and soft tissues.

Rett syndrome A rare neurological disorder that predominantly affects females, marked by progressive neurological deterioration, seizures, and cognitive impairment.

Robin sequence. See Pierre-Robin syndrome.

rooting reflex Newborn reflex in which the infant turns his head toward the hand or nipple stroking his cheek and initiates sucking.

rotary chewing Movement of jaw side to side and up and down to grind and mash food; a mature developmental feeding stage in which a wide variety of food textures can be handled.

Rubinstein-Taybi syndrome A genetic disorder characterized by short stature, intellectual disability, feeding difficulties, distinctive facial features, and broad thumbs and great toes.

rumination An underdiagnosed chronic motility disorder characterized by unintentional regurgitation of food due to the involuntary contraction of the muscles around the abdomen; food may be chewed, swallowed again, or spit out.

Sandifer sign Condition that involves spasmodic torsional dystonia with arching of the back and rigid opisthotonic posturing, associated with symptomatic gastroesophageal reflux, esophagitis, or hiatal hernia.

scoliosis Condition in which the spine curves or twists into a C or S shape; associated with some congenital and neurological disorders.

seizure disorder Involuntary movement or changes in consciousness or behavior brought on by abnormal bursts of electrical activity in the brain; seizures can be classified as general or partial; when seizures occur repeatedly they are diagnosed as epilepsy.

sickle cell disease An autosomal recessive genetic, blood disorder of red blood cells that assume an abnormal, rigid, sickle shape.

sitting height Length between a child's head and buttocks; sometimes used as an estimator of height in children who are able to sit up. The child sits on a box in front of the stadiometer, and then the box height is subtracted from the stadiometer measurement to obtain sitting height.

skeletal dysplasia A group of congenital abnormalities of the bone and cartilage that are characterized by short stature.

spastic Increased muscle tone and stiffness; descriptor for cerebral palsy.

Special Olympics An international program of year-round sports training and athletic competition for children and adults with intellectual disability.

Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) A federal program providing food, infant formula, and nutrition education to pregnant and breastfeeding women, infants, and children younger than 5 years of age.

spina bifida A congenital defect when an area of the spinal column does not close, leaving a section of the spinal cord and spinal nerves exposed through an opening in the back; higher lesions result in greater limitations in mobility; presence of Chiari 2 malformation can result in dysphagia; long-term nutritional risks include overweight/obesity, constipation, and reduced energy needs; mild to severe intellectual disabilities may also be present; also called myelomeningocele.

State Children's Health Insurance Program (SCHIP) A federal Medicaid children's health insurance program created in 1997; optional program for states to offer uninsured or underinsured children who do not qualify for Medicaid; the program has different names in each state.

static encephalopathy A general term for brain damage that is chronic and nonprogressive.

steatorrhea Excessive amount of fat in the feces; stool characterized by light color and offensive odor; feces float.

sucking A more mature up-and-down movement of the tongue and jaw, with negative pressure, to extract liquid from a nipple.

suckling The earliest intake pattern in infants; the lower jaw and tongue elevate and move back and forth, using pressure on the nipple to extract fluid during feeding; replaced by sucking.

Supplemental Nutrition Assistance Program (SNAP) Government-sponsored program providing vouchers to use to purchase food, formerly named Food Stamps. Many programs at farmer's markets accept SNAP benefits.

Supplemental Security Income (SSI) Federal- and state-funded program that provides supplemental income for children with disabilities in low-income families.

texture Consistency of food at the time it is served; generally based on the amount of mastication required before swallowing.

Tolerable Upper Intake Level (UL) The maximum level of daily nutrient intake that is likely to pose no risk of adverse effects for almost all individuals in the general population; unless otherwise specified, the UL represents total intake from food, water, and supplements; ULs are not established for vitamin K, riboflavin, vitamin B12, pantothenic acid, biotin, or carotenoids.

tongue lateralization Ability to move the tongue voluntarily from side to side from its midline position; developmental stage in feeding that signals the ability to manipulate food inside the mouth.

tongue retraction Involuntary tongue movement toward the back of the mouth on presentation of food, spoon, or cup; blocks the normal steps to swallowing.

tongue thrust Forceful protrusion of the tongue, often in response to an oral stimulus, such as a spoon or food; interferes with moving food from the front of the mouth to the back for swallowing.

tonic bite reflex Involuntary bite reflex with associated tension; the bite is not easily released (eg, appears that child is biting spoon or finger and cannot release it).

Total Energy Expenditure (TEE) The intake that meets the average energy expenditure of individuals at the reference height, weight, and age.

tracheomalacia Softening of the cartilage rings in the trachea; results in feeding difficulties with risk of apnea and aspiration during eating.

transpyloric feeding Nutrition support in which a tube extends from the nose through the stomach, past the pyloric valve, into the first part of the small intestine; used primarily when the person is at risk for aspiration of stomach contents.

triceps skinfold measure Measurement of the skin and subcutaneous fat layer around the triceps muscle; used with arm circumference measurement to estimate fat and muscle stores.

trisomy 13 A genetic disorder where there are three copies of chromosome 13; results in a syndrome characterized by severe intellectual disability and many physical abnormalities, such as congenital heart defects; brain or spinal cord abnormalities; very small or poorly developed eyes; extra fingers or toes; cleft lip with or without cleft palate; and weak muscle tone (hypotonia). Also known as Patau syndrome.

trisomy 18 A genetic disorder where there are three copies of chromosome 18; associated with abnormalities in many parts of the body; slow growth before birth and a low birth weight; heart defects; a small, abnormally shaped head, a small jaw and mouth, and clenched fist with overlapping fingers. Also called Edwards syndrome.

trisomy 21 A genetic disorder with an extra 21st chromosome; characterized by short stature, low muscle tone, cardiac and gastrointestinal problems (including celiac disease, intellectual disabilities, and distinct facial appearance). Also called Down syndrome.

Turner syndrome Disorder in females from the absence of one X chromosome; marked by short stature, ovarian failure, and heart defects.

upper gastrointestinal (UGI) endoscopy A procedure that uses an endoscope to view the inside lining of the esophagus, stomach, and small intestine (duodenum).

very low birth weight (VLBW) Premature infant who weighs less than 1,500 g (3.5 lb) at birth.

Videofluoroscopic swallowing study (VFSS) A radiologic study of the oral and pharyngeal cavities to evaluate the swallowing mechanism; foods and liquids are mixed with barium and the study is recorded for assessment and review; also called modified barium swallow study.

weight-age equivalent Age at which current weight would fall at the 50th percentile on the weight-for-age growth chart.

Williams syndrome A genetic condition that is present at birth and can include cardiovascular disease, developmental delays, and learning challenges, and striking verbal abilities.

xerostomia The subjective sensation of dry mouth, which is often (but not always) associated with hypofunction of the salivary glands.

z score A *z* score reflects how many standard deviations above or below the population mean a raw score is. For instance, on a scale that has a mean of 500 and a standard deviation of 100, a score of 450 would equal a *z* score of (450 – 500)/100 = –50/100 = –0.50, which indicates that the score is half a standard deviation below the mean.

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POCKET GUIDE TO

Children With Special Health Care and Nutritional Needs

SECOND EDITION

This fully updated second edition addresses the nutrition care of children with special health care needs, including Down syndrome, autism, cerebral palsy, cystic fibrosis, Prader-Willi syndrome, seizure disorders, and more. Highlights include:

- guidelines for assessing growth;
- recommendations for nutrition screening, assessment, and intervention;
- practical advice for addressing feeding and eating issues, managing enteral nutrition, and working with community services and programs;
- updated information on pediatric nutrition assessment and malnutrition indicators;
- new chapters covering the nutrition focused physical exam and transitioning special health care needs of children to adult care; and
- case studies throughout to illustrate application of the Nutrition Care Process and strategies for providing nutrition care.

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