

Nutrition Module

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Introduction

Like most health care disciplines, nutrition includes aspects of many basic sciences:

- physiology
- biochemistry
- food science

In addition, nutrition includes the effects of environment, disease, infections, medication, and trauma on metabolism. Nutritionists incorporate this knowledge into the assessment of the nourishment of individuals and groups, and then use educational and counseling techniques to develop and implement recommendations for change.

The nutritionist who works with children with special health care needs has training in pediatric nutrition. This includes an understanding of:

- typical growth and development
- feeding skills
- nutrient requirements for growth and development
- special health care needs
- effects of medical conditions (including physical and metabolic problems and medications) on nutritional status

Who Provides Nutrition Services?

Nutrition services are provided by Registered Dietitians (RDs) or Registered Dietitians Nutritionists (RDNs). RDs or RDNs work in a variety of settings (see below). Depending on the institution or organization, their job title may include the terms "nutritionist" or "dietitian." More information about the requirements for the RD credential can be found in the Training and Certification section of this module. At CHDD RDs or RDNs are called nutritionists.

Services Provided in a Variety of Settings

Nutritionists provide services in a variety of settings. For example, some nutritionists provide clinical services in a hospital setting, overseeing parenteral and enteral nutrition of critically-ill individuals. Other nutritionists work in health departments, developing broad nutrition-related educational messages for communities. Still other nutritionists work as managers, supervising the food service aspect of care in hospitals, schools, and other institutions.

History



Post-Civil War

Infant mortality was exceedingly high. Child labor was common. Problems of communicable disease, poor sanitation, and lack of knowledge about child hygiene were major challenges. The development of voluntary agencies was beginning and children's hospitals and state health agencies were developing. Public schools assumed a greater role in the detection and control of childhood illness.

- 1855 - the first children's hospital is developed
- 1860 - Abraham Jacobi, MD begins formal courses in pediatrics and teaches infant nutrition
- 1872 - the American Public Health Association is organized
- 1877 - fourteen states have established state health agencies
- 1898 - school lunches are introduced in New York City schools
- 1895 - milk stations are established in New York City and Rochester (1897) to provide safe milk for infants and children and to educate parents about child hygiene and feeding
- 1897 - services for crippled children (CCS) are initiated in Minnesota, and special schools for children who are deaf, blind, or mentally retarded are developed



1900-1909

Child labor is still common. Voluntary agencies have a major role in child health, and the federal government's role is just beginning to develop. Advances in knowledge in pediatrics, obstetrics, environmental sanitation, and nutrition are under way.

- Municipal nursing services begin to develop, primarily in voluntary agencies such as Visiting Nurse Associations
- Organized prenatal care begins in Boston
- Pasteurized milk is introduced



1910-1919

World War I is declared. Food supplies as well as many other aspects of national life are affected. State and local health agencies become more aware of maternal and child health issues. Schools of public health are being organized, and the role of the federal government in maternal and child health is expanding. The US food administrator initiates a food campaign to familiarize the American people with nutrition concepts.

- 1915 - The discovery of vitamins and the elucidation of their role exert a major influence on infant nutrition
- 1917 - Frances Stern and Lucy Gillett are pioneers in community nutrition work in Boston
- 1918 - The first nutrition publication, Milk the Indispensable Food for Children, is developed by the Children's Bureau and makes a plea for giving priority to infants and young children in allocating inadequate supplies



1920-1929

The idea that child health is a public responsibility has gained more acceptance. Waves of immigration are underway. Congress provides direct federal funding for personal health services, but controversy about the appropriate role of government in such services continues. Rapid progress is being made in pediatrics and infant nutrition. There is growing awareness of the different contributions of the various health disciplines to maternal and child health, and their different roles.

- 1920 - Nutrition studies of children in selected geographic areas of the nation are initiated by the Children's Bureau
- 1921-1929 - The Sheppard-Towner Act is enacted and results in the development of full-time MCH units in the state health agencies. States give considerable attention to nutrition services and employ nutrition personnel
- The Children's Bureau publishes height and weight tables for children under six years of age for use by health workers and issues a publication, Nutrition Work for Preschool Children, which provides one of the first descriptions of the activities of nutrition workers on behalf of preschool children
- The American Child Health Association expands its scope of interest to include nutrition



1930-1939

Severe economic depression affects the well-being of children. As the depression deepens, there is a decrease in available medical care for children, an increase in undernutrition, and an increase in maternal mortality. The science of nutrition expands.

- 1930 - Nutrition is a major concern of the 1930 White House Conference, which focuses on child growth and development
- 1935 - Nationwide food consumption survey is initiated by the USDA
- 1935 - Title V of the Social Security Act is passed and provides for three grant-in-aid programs, Maternal and Child Health, Crippled Children's Services, and Child Welfare. Nutrition positions are established in state health agencies and progressively increase in number as a result of the availability of Title V funds
- 1936 - The Children's Bureau employs its first nutrition consultant, Marjorie Heseltine. She provides national leadership and is a pioneer in the development of nutrition services in maternal and child health.
- 1939 - Emergency relief and food assistance for people in need receive high priority, and the Food Stamp Program is created



1940-1949

World War II results in food rationing, more women entering the work force, and growth of day care programs. There is rapid scientific progress in the knowledge of nutrition, medicine, and public health

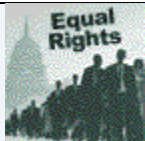
- 1940 - The 4th White House Conference on Children addresses problems of nutrition and includes nutrition services among its recommendations
- 1941 - The National Nutrition Conference results in the development of Recommended Dietary Allowances
- 1941 - A second nutritionist, Helen Stacey, is added to the staff of the Children's Bureau.
- 1943 - Graduate Training Programs in Public Health Nutrition are developed and Title V funds are made available for a nutrition training program
- 1946 - The National School Lunch Program is established



1950-1959

There are some economic advances during the decade. Financing of health services and medical care, however, remains a significant problem for many. Concern for the welfare of children with handicaps, including mental retardation, grows. Significant advances in medicine include the discovery of the polio vaccine and more awareness of the role of nutrition in treatment and rehabilitation..

- The Children's Bureau develops workshops on nutrition and diet in relation to mental retardation to upgrade the knowledge and skills of nutrition personnel in this area and provide a basis for the planning and development of nutrition services
- The Indian Health Service, Public Health Service, establishes a nutrition unit to expand and improve nutrition services to Native Americans and Alaska natives
- Nutrition Practices: A Guide for Public Health Administrators is published by the American Public Health Association



1960-1969

Civil rights and the war on poverty are important national issues. A massive amount of legislation is enacted which increases intervention and service programs targeted toward low-income groups. A new set of child health problems begin to emerge (e.g., increases in substance abuse, adolescent pregnancy, venereal disease, and child abuse). Concern with environmental issues escalates, as does national alarm about the prevalence of hunger. University Affiliated Programs are developed and include nutrition services and training as an important interdisciplinary component.

- 1964 - The Head Start Program is established and includes a nutrition component
- 1964 - Dietary consultation services in states continue to expand (e.g., New Jersey surveys feeding practices in a sample of pediatric units of hospitals)
- 1966 - The Child Nutrition Act is passed and expands food programs for children
- 1967 - Title V funds support establishment of an intensive course in pediatric nutrition to upgrade knowledge and skills of nutrition practitioners
- 1968 - Supplementary Food Programs for Low Income Groups Vulnerable to Malnutrition are initiated by the USDA



1970-1979

Federal legislation and program changes continue to have an impact on maternal and child health services. Findings from several national nutrition studies document the prevalence of nutrition-related disorders among children. Coordination of services receives more attention, including legislative

requirements for coordination.

- 1972 - The Special Supplemental Food Program for Women, Infants, and Children (WIC) is established as an adjunct to health care
- 1977 - The Nutrition Education and Training Program is established
- 1978 - Guide for Developing Nutrition Services in Community Health Programs is published
- 1978 - The Child Care Food Program becomes a permanent program and serves child care centers, settlement houses, recreation centers, institutions for the handicapped, and other group care facilities



1980-1989

Programs known as Crippled Children's Services are renamed Children with Special Health Care Needs. Key federal figures and initiatives bring attention to family-centered care and cultural awareness. Nutrition services focused on using a family centered approach with consideration of culturally appropriate services. Laws also ensured access for infants and toddlers with developmental disabilities to early intervention services which can include nutrition.

- 1985: Crippled Children Services is renamed Children with Special Health Care Needs to reflect the population of children served, which include children with any disability or chronic illness.
- 1986: Amendment to the Education for the Handicapped Act (EHA) mandates that states provide early intervention services from birth.
- 1987: The Surgeon General defines the concept of family centered care for the first time.
- 1989: MCH Ethno-cultural initiatives are launched



1990-1999

Legislation and policies continue to emphasize disease prevention and early intervention among young children. IDEA (Individuals with Disabilities Education Act) ensures a free and appropriate public education based on individuals needs including modified school meals at no extra cost for medical or special dietary needs.

- 1990: Bright Futures, a comprehensive set of child health supervision guidelines, is released with a separate publication of nutrition guidelines for infancy through adolescence.
- 1995: The Office of Child Development creates Early Head Start to address the need for services for low-income, young children under 3 years of age.
- 1998: The U.S. Food and Drug Administration (FDA) starts requiring manufacturers to add folic acid to enriched breads, cereals, flours, and other grain product to decrease the risk of neural tube defects in infants



2000-present

Nutrition health is recognized as part of the life course framework, Newborn screening is expanded requiring increased nutrition services for many conditions. Obesity in all ages increases with a subsequent nationwide focus on prevention and intervention. There is increased awareness of autism spectrum disorders (ASD). Nutrition and feeding concerns are recognized in many children with ASD. Nutrition revisions occur in both the WIC food package and school meals.

- 2006: Combating Autism Act (renamed Autism Collaboration, Accountability, Research, Education, and Support Act or Autism CARES Act in 2014) is enacted with the goal of developing a system of services, conducting early, interdisciplinary evaluations, and providing evidence-based, early interventions.
- 2014: Newborn screening law in Washington State is revised to require timely screening for all infants born in any setting in the state of Washington.

This information was adapted from Egan MC, Oglesby AC. Nutrition services in the Maternal and Child Health Program: a historical perspective. In: Sharbaugh CO (Ed.) (1991). Call to Action: Better Nutrition for Mothers, Children, and Families. Washington DC: National Center for Educational and Child Health.

Informed Clinical Decisions

The nutrition care process includes screening to identify problems and concerns and referral to a qualified nutrition professional for a complete assessment. A nutrition care plan that is appropriate for the child and family is developed with the results of the nutrition assessment.

In this section, the following aspects of the nutrition care process will be reviewed:

Screening

Why nutrition screening is done

The goal of nutrition screening is to identify children who are at risk for nutrition problems. These problems can include an inadequate nutrient intake, inappropriate food selection, and problems with growth and development. Incidence of nutrition risk is higher among children with special health care needs, as high as 40%.

Who performs nutrition screening tasks

Screening is typically performed by non-nutrition health care professionals, such as primary care providers, therapists, and nurses. Nutrition concerns are also identified by educators, parents, and early intervention providers. Examples of nutrition screening are described in the links below.

Examples of nutrition screening are described below:

Cecil is a nurse at a *Head Start* program

Each fall, he conducts a nutrition screening program to identify children who may be at risk for nutritional problems. The *Head Start* screening program includes evaluation of:

- weight-for-age, height-for-age, and Body Mass Index-for-age
- *hematocrit*
- parent-completed nutrition questionnaire to identify parent concerns, feeding skills, and *food security*

Head Start – federally-funded preschool program for children ages 3 to 5 years from low-income families; includes children with special needs; educational program for children and parents; includes some health screenings

hematocrit – a measure of the number of red cells found in the blood; a hematocrit less than the reference range can indicate anemia

Cecil coordinates referrals to the *Head Start* program's nutritional consultant (a Registered Dietitian) for those children who are identified to be "at risk."

food security – access to nutritious and safe foods in socially acceptable ways

Mary is a nurse on the medical floor of a children's hospital

She completes an interdisciplinary admissions form for each child who is admitted during her shift. This form includes several nutrition-related questions:

- weight-for-age, length-for-age or height-for-age, and weight-for-length or Body Mass Index-for-age
- usual food pattern (type of foods, feeding skills)
- special diet
- parent concerns about nutritional status, feeding skills, and food security
- medical condition(s)

A Dietetic Technician, Registered (DTR) compares this information to established nutrition risk criteria, and the child is identified at low, moderate or high nutritional risk. Based on this evaluation, a plan is developed for a complete assessment by a Registered Dietitian or for re-screening.

Gloria is the program coordinator at an *early intervention program*

A nutrition screening form is completed at a child's initial visit to the center. It includes evaluation of:

- growth parameters (weight-for-age, length-for-age or height-for-age, weight-for-length or Body Mass Index-for-age)
- usual food pattern (type of foods, feeding skills)
- special diet
- parent concerns about nutritional status, feeding skills, and food security
- medical condition(s)

early intervention services – established by Part H of P.L. 97-457 of 1986 (now Part C of the IDEA of 1997); community-based therapeutic and educational services for infants and children under 3 years of age with developmental delays

Then, the nurse compares this information to established criteria, and if necessary, a referral to a Registered Dietitian is coordinated. Members of the early intervention team are also able to make nutrition referrals whenever they identify a nutrition-related issue.

What information is included in the nutrition screening process

Criteria for nutrition risk are defined by the institution. In most instances, the following nutrition-related factors are evaluated:

Growth

Growth is evaluated by measuring weight and length (for children 0-3 years) or weight and stature (for children 2-20 years) and plotting the measurements on age-specific growth charts. Weight-for-length (0-3 years) and body mass index-for-age (2-20 years) are also used. More information about evaluating growth can be found on this website: <http://depts.washington.edu/growth>

Inappropriate growth can be indicated by:

- weight gain too slow or too rapid for length
- weight-for-age and/or length-for-age <5th percentile
- weight-for-length or **BMI**-for-age <5th percentile
- **BMI**-for-age >85th percentile

body mass index (BMI) – an indicator of weight and stature proportionality; $BMI = \text{weight (in kilograms)} / \text{height (in centimeters)}^2$

**Dietary intake**

Nutrition risk can be indicated by inappropriate dietary intake; the amount and type of food/formula offered to (and accepted by) a child can provide important information.

An inappropriate or inadequate diet can be indicated by:

Inappropriate growth can be indicated by:

- formula not prepared properly (too concentrated or diluted, addition of solids or cereal)
- solids given before developmental age of 4-6 months
- excessive solids given in infancy so that breastmilk or formula is significantly reduced
- toddlers who are not offered (or who refuse) foods from one or more major food groups
- limited intake that excludes large numbers or entire groups of foods; may be due to pickiness, inability to eat some textures, or foods not offered
- excessive intake of juice, carbonated drinks, sweets, salty snacks, and other foods of low nutrient intake

- foods that are hard to chew or unsafe (nuts, raw vegetables, hard candy, popcorn) are offered before 3-4 years of age
- inappropriate or excessive use of supplements

Feeding skills and mealtime behaviors

Problems with feeding skills and behaviors can be indicated by:

- Finger food and textured foods not offered by developmental age of 6-8 months
- Cup and spoon not offered by 9-12 months developmentally
- Bottle use continued after 18 months
- Infant not allowed to feed on demand
- Lack of routine meals and snacks; child allowed to “graze”
- Child is allowed to dictate menus
- Meals take less than 10 minutes or more than 40 minutes
- Caregiver unable to read or respond to child’s cues for hunger and satiety
- Limited food resources for family
- Lack of caregiver knowledge regarding nutrition and feeding percentile



Medical Conditions

- Tube-feeding
- Conditions associated with oral motor problems or delays
- Food/formula allergies or intolerance
- Conditions that alter nutrient needs or feeding (e.g., pulmonary disorders that increase energy needs, renal conditions that alter fluid and electrolyte needs)
- Medications that alter appetite and/or nutrient absorption and metabolism

Family questions or concerns

Food security

A list of nutrition-related red flags, "[Risk Factors for Nutrition, Growth and Feeding in Infants and Young Children](#)" is available (pdf).

When nutrition screening is performed

Each institution/system has its own schedule for nutrition screening. For example, participants in the [Head Start Program](#) are screened annually. Children who are admitted to hospitals are screened upon admission and regularly (e.g., every 3-7 days) during the admission.

What practitioners can do when nutrition-related problems are identified

When nutrition problems are identified, a referral should be made to a Registered Dietitian who specializes in nutrition services for children with special health care needs. Resources for identifying nutrition services for children with special health care needs are included in the **Resource** section of this module. Also included are samples of screening tools.

Self Test

Question 1: Which of the following is **NOT** a "red flag" that might indicate an inappropriate or inadequate dietary intake?

- a. preference for salty foods
- b. excessive intake of juice
- c. solids given before developmental age of 4-6 months
- d. formula not prepared properly

Question 2: Which of the following is **NOT** a "red flag" that might indicate the need for a referral to a nutritionist?

- a. concern that a child's slow growth rate is related to a renal disorder
- b. concern that a child's slow growth rate is related to a genetic condition
- c. concern that a child has delayed oral-motor skills
- d. concern that a child's inadequate intake is contributing to her slow growth rate

Self Test Answers to Questions 1 & 2

Assessment

Why nutrition assessment is done

Assessment of an individual's nutritional status is conducted when nutrition risk is identified by a screening tool. Assessment includes a detailed look at the risk factors and a determination of whether or not intervention is necessary. If intervention is necessary, the assessment process will likely include the development of an intervention plan with the family.

Who performs nutrition assessment tasks

Nutrition assessment is completed by a nutrition professional, usually a registered dietitian. Because nutritional status involves so many factors (e.g., physical development, motor skills, behaviors), interdisciplinary assessment is often useful as well. Often, "feeding teams" provide assessment and intervention recommendation.

What information is included in the nutrition assessment process?

Assessments take a closer look at many of the factors evaluated by screening tools:

Growth

Typically, weight and stature (or length for children under 2 or 3 years of age) are measured and plotted on growth charts. Body Mass Index ([BMI](#)) (or weight-for-length for children under 2 or 3 years of age) is also assessed. Nutritionists evaluate a child's growth pattern over time.

A child's medical condition is also considered (for example, does the child have a genetic condition that is associated with short stature?). When appropriate, a specialty growth chart may be used to augment evaluation of growth. (Specialty charts are appropriate when a condition affects an individual's genetic growth potential.)

Read more about [condition-specific CDC growth chart page](#).

Inappropriate growth can be indicated by:

- weight gain too slow or too rapid for length
- weight-for-length or [BMI](#)-for-age <5th percentile
- weight-for-age and/or length-for-age <5th percentile
- BMI-for-age >85th percentile

Other measurements sometimes used include **arm circumference** and **triceps skinfold**. These are indirect estimates of protein and fat stores. They require accurate, calibrated equipment and a trained and practiced measurer.

Application of these measures is limited for children with atypical body composition (e.g., [hypotonia](#) or [hypertonia](#)).

arm circumference – measurement used to aid in the estimation and assessment of muscle and fat mass, used in conjunction with triceps skinfold measurement

triceps skinfold – measurement of the skin and subcutaneous fat layer around the triceps muscle, used with arm circumference measurement to estimate fat and muscle stores

hypotonia – decreased muscle tone

hypertonia – increased muscle tone

food record – parents and caregivers record all foods offered to and eaten by their child in a specified (usually 3 or 7 days) period. Information to make the record accurate includes detailed portion sizes and methods of food preparation



Dietary Intake

Dietary intake is evaluated and compared to [Dietary Reference Intakes \(DRIs\)](#), the recommended intake levels. Information about intake can be collected through detailed *food records*, *diet recalls*, and *feeding histories*.

diet recall –parents or caregivers describe the types and amounts of food eaten in a specified (usually 24 hours) period; often used as a screening tool

feeding history –parents and caregivers are interviewed to determine a child’s usual intake and feeding history (including information about intake, feeding skills, and eating environment)

The nutritionist considers the effect of

a child’s medical condition and medications on his nutrient needs and includes this in the overall evaluation.

Read more about the effects of *medication* on nutritional status.

Medication-nutrient interactions are considered during a nutrition assessment. Some medications affect the intake, absorption, metabolism, and excretion of nutrients. The efficacy of other medications can be affected by food. Administration of medication can influence the timing of meals and snacks. For example, a medication that is given several times per day without food might make it difficult to schedule a meal or snack.

Medications with known nutrient interactions include:

- anticonvulsants
- stimulants
- laxatives
- antibiotics
- antidepressants
- steroids

Also explored is the pattern of intake. Are appropriate portion sizes offered? Is the child eating at appropriate intervals? What is the mealtime environment?

Other questions include: Does the child take any supplements? Is an alternative diet used or are any foods (e.g., cow’s milk or wheat) restricted? Does the child’s food pattern promote oral health? How is food prepared? Do cultural or religious practices affect food choices?

Intake Feeding skills/problems

Many children with developmental disabilities have problems with feeding skills. The nutritionist evaluates the effects of these problems on the child’s intake and nutritional status. Often, a nutritionist will work with a feeding therapist (e.g., speech, occupational, and physical therapists), to develop a plan when feeding problems are suspected. In some situations a formal feeding team exists.

Read more about *feeding teams*.

A feeding team is a multi- or interdisciplinary team.		
The team is usually made up of a combination of the following health care professionals:	Together, the team evaluates:	Assessment and Intervention may include:
<ul style="list-style-type: none"> • physician • nutritionist • nurse • social worker • occupational therapist • physical therapist • speech pathologist • behavioral psychologist 	<ul style="list-style-type: none"> • oral motor skills • behavior and mealtime interaction • dental health • adequacy of dietary intake • caregiver expectations 	<ul style="list-style-type: none"> • assess dysphagia and risk of aspiration • proper positioning • proper food texture • therapeutic feeding techniques • appropriate duration of meals • appropriate amount of food/fluids • tube feeding for part or all of needs

Medical conditions/clinical

The effects (and potential effects) of a medical condition on growth, feeding skills, and dietary intake are considered in a nutritional assessment. For example, does the child's medical treatment include the use of a medication that can affect his nutrient needs? Risk for nutritional problems is higher for children with conditions with motor or cognitive delays that limit self-feeding and medical complications that affect energy and other nutrient needs (e.g., gastrointestinal problems, cardiac and pulmonary involvement).

Family questions or concerns

Concerns that the family has about the child's nutritional status and dietary intake are addressed in a nutritional assessment.

Food security

The family's access to nutritious, appropriate foods for their child is an important piece of a nutritional assessment. Is the family consistently able to purchase foods to meet their child's nutrient needs? Is the family connected to resources and services that can address unmet needs?

Biochemical data

When appropriate, the nutritional assessment also includes evaluation of biochemical data. Sometimes, measures of nutritional status (for example, vitamin levels or prealbumin) are included in blood draws. Some conditions may require routine monitoring of specific laboratory indices. For example, the diet prescription for a child with a renal disorder may be adjusted depending on serum phosphorus levels.

Intervention: Reaching an informed clinical decision

Nutrition interventions are developed with input from the family, the nutritionist, and other members of the health care team. Nutrition interventions should be evidence-based and include a plan for implementation, monitoring, and follow-up.

Effective nutrition interventions address medical and nutritional concerns; other factors that influence nutrition status are also considered:

- financial constraints for the family
- nutrition misinformation (e.g., messages from the media, other family members)
- cultural and religious differences
- varying caregiver expectation
- support systems

Intervention Examples: Micah, Bonnie, and Sydney

Micah, a 3-year old with autism

Micah is a 3-year old who is being evaluated by the Child Development Team; he has autism. The team has made recommendations for therapy for Micah in his community.

Micah also has nutrition-related issues. He eats a very limited selection of foods and refuses to eat fruits and vegetables. His family is concerned that his nutrient needs are not being met.

The nutritionist completes an assessment. Micah's growth pattern is appropriate, but his food pattern is not providing adequate amounts of many vitamins and minerals. Micah receives a WIC food package, and is regularly seen at the WIC Office.

The nutritionist explains that Micah's food-related behaviors are not uncommon among children with autism and describes some strategies that have worked for other families. Micah's family, and the rest of the team develop a set of interventions:

- Micah's family selects a behavior-related strategy; they will offer a vegetable to Micah each night at dinner but will not force him to eat it. If he decides to try the vegetable, they will praise him.
- Micah's family will give him a multiple vitamin supplement.
- The nutritionist will identify a community nutritionist to work with Micah's family on a long-term basis. In addition, Micah's growth can be monitored through regular visits to the WIC Office.

Bonnie, an 8-year old with phenylketonuria

Bonnie is an 8-year old who has phenylketonuria (PKU). She attends PKU clinic monthly, so has regular visits with the clinic physician, nutritionist, and social worker.

Bonnie and her family do a nice job of managing PKU, and Bonnie's blood phenylalanine levels are typically in the desired range.

The clinic nutritionist completes a nutrition assessment for Bonnie annually, ensuring that her nutrient needs are met by her formula and food prescription.

Nutrition interventions for Bonnie include:

- Bonnie will be offered (and will consume) phenylalanine-free formula that meets 85% of her energy and protein needs and 100% of her vitamin and mineral needs.
- Bonnie's food intake is limited to <300 mg phenylalanine per day; this will help to ensure that her monthly blood levels are in the desired range.
- Bonnie's school lunch will be appropriate for a child with PKU. The clinic physician and nutritionist help Bonnie's parents request a 504 Accommodation Plan each year.

Sydney, an 18-month old with trisomy 21

Sydney is an 18-month old who has trisomy 21. She has a cardiac condition that increases her energy needs and had early feeding problems. Sydney has a gastric feeding tube because she is not able to eat enough food orally to meet her nutrient needs. She is seen in an early intervention center, where she has regular visits with the occupational therapist, speech therapist, and nutritionist.

The occupational therapist helps to address oral-motor issues and helps the family to incorporate different textures into Sydney's meals and snacks. The nutritionist helps to ensure that Sydney's nutrient needs are met as her intake changes.

Nutrition recommendations for Sydney include:

- appropriate intake of formula through Sydney's feeding tube to meet energy, protein, and vitamin and mineral needs as her oral intake increases
- appropriate composition of formula to avoid nutrient-medication interactions
- timing of meals, snacks, and tube feedings to reinforce feelings of hunger and satiety and to fit with the family's daily schedule
- regular monitoring of growth and adjustment of recommendations for food and formula intake

Challenges

Related to Nutrition and Children with Special Health Care Needs

Nutrition assessment and intervention for children with special health care needs presents a number of challenging issues:

- **Feeding is an integral part of parenting.** Because of this, information provided by caregivers may be influenced by feelings of adequacy in this area. Nutrition professionals must also consider this when making recommendations to families.
- **Energy and nutrient requirements vary from child-to-child;** factors include genetics, body composition, activity/mobility level, medical condition, medications, chronic infections, and reduced weight bearing capacity.
- **It can be difficult to obtain accurate and reliable dietary intake information,** especially when the information is provided by a number of care providers.
- **The use of vitamin and mineral supplements, other nutritional products and unproven dietary regimens** can present challenges as well. Families of children with developmental disabilities can be particularly susceptible to the marketing appeal of supplements and products and to undocumented nutritional therapies found in the mass media and on the Internet.

These challenges make an individualized approach to nutrition care necessary and underscore the need for referral to a Registered Dietitian with training in nutrition for children with special health care needs.

Nutrition Service Models

Nutrition services for children with special health care needs are provided in a variety of settings, through direct service, consultation, and policy setting. Several examples of nutrition services are listed below.

Direct Service

Nutritionists who provide direct services meet with children and their families to develop a comprehensive nutrition care plan. The frequency of follow-up will depend on the individual's needs.

- Hospitals (community and tertiary care centers; inpatient and outpatient)
- Specialty clinics
- **WIC** programs
- **Early intervention programs**
- Registered Dietitians in private practice

WIC – USDA Supplemental Nutrition Program for Women, Infants, and Children; a federally-funded community program that provides foods, infant formula, and nutrition education to pregnant women, infants, and children under 5 years of age, and breastfeeding mothers

early intervention services – established by Part H of P.L. 97-457 of 1986 (now Part C of the IDEA of 1997); community-based therapeutic and educational services for infants and children under 3 years of age with developmental delays

Consultation

Nutritionists who provide consultative services may or may not meet with children and their families. They might meet with or observe a family and provide specific recommendations to other care providers (e.g., therapists or educators). Alternatively, they may provide general recommendations to promote appropriate nutrition goals for an entire program.

- Public health departments
- Child nutrition programs (e.g., Child Care Food Program, School Lunch and Breakfast Programs)
- **Head Start** and **ECEAP** programs

Head Start – federally-funded preschool program for children ages 3 to 5 years from low-income families; includes children with special needs; educational program for children and parents; includes some health screenings

Early Childhood Education Assistance Program (ECEAP) – is a preschool program funded by Washington State; services provided by Head Start and ECEAP are similar

Policy

Nutritionists are also involved in setting nutrition policies, such as the types of services provided by programs.

- Public health departments
- **State Children with Special Health Care Needs programs**
- Federal programs

CSHCN Program –Title V: Children with Special Health Care Needs Program funded by the federal Maternal and Child Health Services Block Grants. Each state establishes a program to address the needs of children with special health care needs. Names of state programs vary. In some states, these programs provide direct services or pay for services; in other states, the programs assure services in other ways

Relationships with Other Disciplines

Nutritionists work with families and other health care providers in a number of ways. Several examples are described below.

Feeding Teams

A **feeding team** is one example of a formal (or informal) interdisciplinary team. Feeding teams may be comprised of members who work for the same institution or may be made up of people for a number of organizations.

A **feeding team** is a multi- or interdisciplinary team. The team is usually made up of a combination of the following health care professionals:

- physician
- nutritionist
- nurse
- social worker
- occupational therapist
- physical therapist
- speech pathologist
- behavioral psychologist

- Together, the team evaluates:
- oral motor skills
 - behavior and mealtime interaction
 - dental health
 - adequacy of dietary intake
 - caregiver expectations

- Assessment and Intervention may include:
- assess dysphagia and risk of aspiration
 - proper positioning
 - proper food texture
 - therapeutic feeding techniques
 - appropriate duration of meals
 - appropriate amount of food/fluids
 - tube feeding for part or all of needs

Educational System

Nutritionists can also work with parents and teachers to incorporate nutritional needs and goals into a child's educational plan.

Federal law makes all children in public schools eligible to receive school meals. If a modified meal is necessary, the nutritionist and physician can help families to request the modification using an **IEP** (Individualized Education Plan), **IFSP** (Individualized Family Service Plan), or **504 Accommodation Plan**. The [Diet Prescription for Meals at School](#) is

one tool to help with this process. Many school districts provide specific diet prescription forms. Examples of modified meals include high calorie, low calorie, diabetic, soft, and documented food allergy.

Individualized Education Plan (IEP) – a contract between the school system and the student/family that outlines specific educational plans and goals, as well as actions and a timeline for implementation that can include plans for special health care needs; in place for all children over age 3 years enrolled in special education systems

Individualized Family Service Plan (IFSP) – a document that outlines specific educational plans and goals, actions, and a timeline for implementation that can include plans for special health care needs; in place for all children under age 3 years enrolled in early intervention programs

504 Accommodation Plan – a document outlining the plan for a child who requires health-related services at school, but is not enrolled in a special education program; mandated by the Rehabilitation Act of 1973

Individualized Family Service Plan (IFSP) – a document that outlines specific educational plans and goals, actions, and a timeline for implementation that can include plans for special health care needs; in place for all children under age 3 years enrolled in early intervention programs

If a child receives special education services, nutrition and feeding goals can also be incorporated into a child's IFSP/IEP. For instance:

- progress in oral motor or self-feeding skills
- supporting improved growth, weight gain, or weight loss
- management of eating/mealtime behaviors (e.g., encouraging more food variety for a child with ASD)

Screening

Nutritionists can screen for and make referrals related to other health risks, including:

- delays in feeding skills or eating patterns (referral to an Occupational Therapist or Speech-Language Pathologist)
- problem feeding behaviors and interactions (referral to psychologist, social worker, or nurse)
- oral health problems (referral to dentist or dental hygienist)

Self Test-2

Question 3: Sandy has cerebral palsy and is in second grade; she receives special education services. She needs a soft diet, but can feed herself. Which of the following plans might be used to help Sandy get a modified school lunch?

- a. IFSP
- b. IEP
- c. 504 Accommodation Plan
- d. none of the above; Sandy's family must provide her modified meal

[Self Test Answers #3](#)

Training and Certification

Registered Dietitians/Registered Dietitians Nutritionist (RDs/RDNs) provide nutrition services, including medical nutrition therapy. RDs are individuals who have:

- completed the minimum of a bachelor's degree granted by a US regionally accredited college or university, or foreign equivalent that is approved by the Commission on Accreditation for Dietetics Education (CADE) of the American Dietetic Association
- completed a CADE-accredited supervised practice program at a healthcare facility, community agency, or a foodservice corporation, or combined with undergraduate or graduate studies. Typically, a practice program will run six to twelve months in length
- passed a national examination administered by the Commission on Dietetic Registration

- completes continuing professional education requirements to maintain registration

Many RDs/RDNs have graduate degrees, and some hold additional certifications in specialized areas of practice, such as pediatric nutrition, nutrition support, and diabetes education. Other types of advanced training include fellowships and fellowships in areas such as neurodevelopmental disorders and neonatal nutrition.

More information can be found on the website for the [American Dietetic Association](#), the major professional organization for RDs and dietetic technicians.

Licensure and Certification

In addition to RD credentialing, many states have regulatory laws for dietitians and nutrition practitioners. Frequently these state requirements are met through the same education and training required to become an RD.

Washington State has a certification program for nutrition professionals; the credential is Certified Dietitian (CD). For information on other states, visit the website for the [Commission on Dietetic Registration](#).

Code of Ethics and Standards of Practice

A voluntary, enforceable code of ethics exists for RDs who are members of the American Dietetic Association. To view the [Code of Ethics for the Profession of Dietetics](#) at the American Dietetic Association.

Standards of Professional Practice are statements of a dietetics professional's responsibility for providing services. [American Dietetic Association/Commission on Dietetic Registration Code of Ethics for the Profession of Dietetics and Process for Consideration of Ethics Issues](#) (pdf).

Resources

Where do I find the resources to assess nutrition concerns and provide help?

- hospitals (tertiary, community)
- health departments, [WIC programs in WA](#)
- [Washington State Association of Head Start & ECEAP](#)
- early intervention programs
- home health agencies
- child nutrition programs (e.g., school lunch and breakfast)
- [Nutrition for Children with Special Health Care Needs in Washington State](#)

Where do I find information about nutrition issues and children with special health care needs?

- upcoming feature: Gaining and Growing (nutrition follow-up of low birth weight infants in the community)
- [Assuring Pediatric Nutrition in the Community](#) (including resources, guidelines, FAQs, training opportunities)
- [Nutrition Interventions for Children with Special Health Care Needs](#), 3rd ed. Yang Y, Lucas B, Feucht S. Washington state Department of Health, 2010.
- Bright Futures in Practice: Nutrition, 3rd ed. Story M, Holt K, Wooldridge N, Story M, Sofka D, eds. 2011. American Academy of Pediatrics. (<https://brightfutures.org/>)
- Trahms CM, Pipes PL. Nutrition in Infancy and Childhood. 6th ed. WCB/McGraw-Hill, 1997.
- Samour PQ, King K. Pediatric Nutrition, 4th ed. Jones & Bartlett Learning, 2012.

Other resources

- Position Statement of the American Dietetic Association: Providing nutrition services for people with developmental disabilities and special health care needs. Journal of the American Dietetic Association 2010; 110: 206-307. Available online at the [Journal of The American Dietetic Association](#).

Credits and Acknowledgements

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Self Test Answers

Self Test 1

Question 1: The correct response is: **a. preference for salty foods**

Question 2: The correct response is: **Both a. and b. are correct!**

a. concern that a child's slow growth rate is related to a renal disorder

b. concern that a child's slow growth rate is related to a genetic condition

[Back to Self Test -1](#)

Question 3: The correct response is: **b. IEP**

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