Nutrition for Children with Special Health Care Needs

Module 5: Integrating Community Services and Programs
Pre Test

This Pre Test contains 8 multiple-choice questions. It is intended to provide you with some information about material that might require particular attention.

**QUESTION 1**

A 7-year old with oral-motor problems needs a liquid nutritional supplement in order to meet her energy needs. She comes from a family with a very limited income. Which of the following programs might cover the cost of the supplement?

- a. WIC
- b. Medicaid
- c. Commodity Supplemental Food Program
- d. Supplemental Security Income

**QUESTION 2**

Which of the following is provided by SSI?

- a. reimbursement for services included in the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)
- b. reimbursement for services that are not included in the Early and Periodic Screening, Diagnosis and Treatment Program
- c. emergency assistance, including foods, to families with low incomes
- d. a monthly cash payment to children with special health care needs

**QUESTION 3**

Marlon has a food allergy; he gets hives when he eats a food containing eggs. His family has submitted a request from his physician for modified meals. Is it appropriate to include this in a 504 Accommodation Plan?

- a. Yes, the food allergy is a documented medical condition, and Marlon is entitled to a school lunch that does not contain eggs.
- b. Yes, because food allergies are more prevalent now than in the past.
- c. No, a food allergy does not prevent Marlon from receiving an appropriate education.
- d. No, food allergies are rare and Marlon probably does not have a real food allergy.

**QUESTION 4**

Lisa is a 2 ½-year old with Down syndrome who receives early intervention services. Which of the following plans is in place for Lisa?

- a. 504 Accommodation Plan
- b. IEP (Individualized Education Plan)
- c. IFSP (Individualized Family Service Plan)
d. none of the above

**QUESTION 5**

An IEP is a planning document for children in special education. Which of the following statements about IEPs is true?

a. it is renewed every two years
b. it is an interdisciplinary agreement
c. both of the above
d. none of the above

**QUESTION 6**

You are reviewing a website that provides medical and nutrition-related information. Which of the following is the best indicator that the information provided is “good”?

a. there is no information about who sponsors the site
b. the information is written by a person named Dr. Joe Smith
c. the site is well-written and the information is easy-to-understand
d. users can send email questions about the site to the Web Master.

**QUESTION 7**

True or false: Sarah, a 4-year old, needs a feeding therapy. This service is covered under Part C of IDEA.

a. TRUE
b. FALSE

d. none of the above

**QUESTION 8**

The correct response to the previous question was false. Why would Part C of IDEA NOT cover feeding therapy for Sarah?

a. Because Part C funds Title V programs, which do not pay for therapy services.
b. Because Part C funds the Emergency Food Assistance program, which does not provide services.
c. Because Part C funds special education programs, for children older than 5 years.
d. Because Part C funds early intervention services, which are for children ages 0 to 3 years.
Introduction

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

- Identify potential community service providers to help families put nutrition recommendations into practice
- Incorporate nutrition therapy goals into the educational system for children with special health care needs
- Describe other resources for families of children with special health care needs and describe some methods for evaluating web-based information
- Incorporate community resources into a nutrition care plan
Section 1: General Community Service Providers

This section describes services and resources that are available in many communities and that are often critical in implementing nutrition care plans. Services differ between regions, states, and communities, so not all of the resources described will be available in your area. This information may, however, give you ideas for community resources.

Medicaid and EPSDT

**Medicaid** (Title XIX of the Social Security Act) is a program that pays for medical care for eligible families with low incomes. It is funded by federal and state governments, and eligibility, administration, and services vary between states. In many states, special health care needs can also make a child eligible for Medicaid. Medicaid coverage varies from state-to-state. In some states, Medicaid provides reimbursement for nutrition services and/or nutritional supplements and enteral supplies. There may also be mechanisms to cover services by members of feeding teams.

**The Early and Periodic Screening, Diagnosis and Treatment program (EPSDT)** is a component of the Medicaid program for persons under 21 years of age. Children who are eligible for Medicaid are entitled to EPSDT. EPSDT guidelines include screening for nutritional problems, and, when a problem is discovered, services to treat conditions identified by the screening.

An overview of the Medicaid program can be found at: http://cms.hhs.gov
More information about EPSDT can be found at: http://cms.hhs.gov/medicaid/epsdt/default.asp

**SCHIP**
The State Children’s Health Insurance Program (SCHIP) is a program that helps states to expand Medicaid eligibility. Again, eligibility, administration, and services vary between states that participate in SCHIP.

**WIC**
The Supplemental Nutrition Program for Women, Infants, and Children, WIC is a key provider of nutrition services and food vouchers for low-income women, infants, and children who are at nutritional risk. It is a program funded by the Food and Nutrition Service of the USDA.

Eligibility varies between states and counties, but in general, pregnant women or women who are breastfeeding an infant up to age 1 year, children up to age 5 years from families with incomes at or below 185% of the federal poverty level are eligible for WIC. Medicaid eligibility may also make a child eligible for WIC services.

Some WIC agencies are able to provide follow-up services to children with special health care needs and bill Medicaid. In some areas, WIC provides specialized nutritional formulas.

Services provided by WIC include monthly food packages or coupons for food (or formula), nutrition education and counseling, health screening, and referrals for other services.
More information about WIC can be found at: http://www.fns.usda.gov/wic/

**Title V/CSHCN Program**
Title V of the Social Security Act of 1935 established programs for maternity, infant, and child care. In the 1980s, the Maternal and Child Health Services Block Grant was created, establishing a single grant for each state.

Today, Title V Block Grants are administered to US states and jurisdictions by the Maternal and Child Health Bureau of the Health Resources and Services Administration. Title V programs are Federal and State partnerships to develop systems of service for maternal and child health, including children with special health care needs.

Eligibility and services vary between states. In some states, Children with Special Health Care Needs (CSHCN) programs provide direct services or pay for services, including nutrition. In other states, the CSHCN programs assure services by acting as safety nets when services are not provided by another source.

More information about Title V programs can be found at: http://www.mchb.hrsa.gov/

**SSI**
Supplemental Security Income is administered by the Social Security Administration. A monthly payment is available for some children with special health care needs, dependent upon family income level. In many cases, SSI is a “gateway” to other services, and eligibility for SSI can mean that a child is eligible for WIC, Medicaid, and/or the CSHCN Program.

More information about SSI for children with special health care needs is available at: http://www.ssa.gov/pubs/10026.html

**Educational System**
Nutrition goals can be incorporated into a child’s educational plan, and special dietary needs must be accommodated by the public school system. This is covered in more detail in Section 2, Nutrition and the Education System.

**Early Intervention**
Part C of the Individuals with Disabilities Education Act (IDEA) provides funding for early intervention services. This program provides assessment and intervention services for infants and children 0 to 3 years old with developmental delay or other special health care needs. Nutrition services are included in early intervention services. Each state establishes an interagency coordinating council (ICC) to guide its early intervention services.

**Head Start**
Head Start is a program with an overall goal of promoting school readiness for children from low-income families and children with special health care needs. In addition, Head Start provides social health services (including medical, dental and nutrition).
Early Head Start is a similar program, started in 1994, which provides services to pregnant women with low incomes and children 0 to 3 years of age from families with low incomes.

Federal law reserves 10% of enrollment slots for children with disabilities.

More information about Head Start can be found at: http://www2.acf.dhhs.gov/programs/hsb/

More information about Early Head Start can be found at: http://www.ehsnrc.org/

**Food Assistance Programs**

Several food assistance programs are available. They include:

- **Commodity Supplemental Food Program** – funded by the USDA, this program provides canned or packaged foods to pregnant, postpartum, or breastfeeding women and children, with incomes below 185% of the federal poverty level.

- **Food Stamp Program** – funded by the USDA, this program provides coupons for the purchase of foods to families who meet income eligibility requirements. More information about the Food Stamp program can be found at: http://www.fns.usda.gov/fsp/.

- **The Emergency Food Assistance Program** – funded by the USDA, this program distributes foods through local providers (e.g., food banks, soup kitchens) to families with low incomes; eligibility varies between states.

- **Child and Adult Care Food Program (CACFP)** – provides USDA-supported meal reimbursement for childcare providers with low-income eligible children. More information about CACFP can be found at: http://www.fns.usda.gov/cnd/care/cacfp/cacfphome.htm

Resources for CACFP participants can be found at: http://www.nal.usda.gov/childcare
Section 2: Incorporating Nutrition Goals Into The Educational System

Federal regulations require that the public school system accommodate children with special health care needs...including nutrition-related issues:

- **Individuals with Disabilities in Education Act (IDEA) of 1990** – provides federal funds to states and school districts to make free, appropriate public education available to eligible students
- **Section 504 of the Rehabilitation Act of 1973** – an amendment (in 1982) to the Rehabilitation Act of 1973 ensures access to school meal service to students with disabilities
- **Americans with Disabilities Act (ADA) of 1990** – protects persons with disabilities from discrimination

This section describes some of the types of goals and interventions that can be incorporated into a child’s educational plan and reviews some strategies for successfully utilizing this resource.

A number of tools allow nutrition goals or health-related accommodations to be incorporated into the educational plan:

- IEP (Individualized Education Plan)
- IFSP (Individualized Family Service Plan)
- 504 Accommodation Plan

**IEP and IFSP**

IFSP and IEP are plans in place for children who receive special education or who are enrolled in early intervention programs.

- The **IFSP (Individualized Family Service Plan)** is for children (and their families) ages 0 to 3 years enrolled in early intervention programs.
- The **IEP (Individualized Education Plan)** is for children ages 3-21 years who receive special education services.

Both documents are interdisciplinary agreements between the child’s family, teachers, and therapists that are revised at least once per year. They include short- and long-term goals and specify how each goal is to be accomplished, who is responsible for what action, and when specific actions take place.

**An example of nutrition services in an IEP:**

Joseph is a 4-year old with cerebral palsy who is enrolled in a special education preschool classroom. He is underweight and has delayed oral-motor skills.

The nutritionist provided Joseph’s mother with a list of recommendations that could reasonably be incorporated into his school day. This list was reviewed by Joseph’s teachers and therapists, and several nutrition goals were added to his IEP:

- Joseph will drink 4 ounces of PediaSure formula (provided by WIC) during the morning snack period.
- School lunch, supplemented with energy-dense additives, will be offered; the food service coordinator has a list of appropriate additives.
- Joseph will practice lip closure skills and chewing skills in OT sessions.
504 Accommodation Plan

The 504 Accommodation plan is for a child who does not receive special education services, but who needs special, health-related services during the school day.

A 504 Accommodation Plan might be used for a child with vision problems who needs large print materials or for a child with Attention Deficit Hyperactivity Disorder (ADHD) who must sit at the front of the class in order to maintain attention.

An example of nutrition services in a 504 Accommodation Plan:
Cheryl is an 11-year old with type 1 diabetes. To ensure that she eats the morning and afternoon snacks that are prescribed, her family requested a 504 Accommodation Plan with the following:
• Cheryl will be permitted to eat a mid-morning and afternoon snack during recess.
• Cheryl’s family will bring a supply of snacks to the classroom each week.

Nutritional Therapy in the Educational Plan

Interventions can be placed into two categories:
• Modified meals
• Nutrition therapy goals

Modified Meals

The need for special foods or modified meals must be accommodated by the school district in order to allow the child to be included in school activities. Examples of children who need modified meals:
• Ricardo has diabetes and needs a snack at 10 am. He usually takes his snack to school, but his teacher also has a small supply of snacks and a list of acceptable and non-acceptable treats in the classroom.
• Victor, a boy with phenylketonuria, brings low-protein foods to school. He is allowed to select fruits, vegetables, and juice from the school lunch menu, and he keeps his medical food in the classroom refrigerator until lunchtime. These accommodations are written in a 504 Plan.
• Julia has oral-motor problems and cannot chew; she is not in a special education program. Soft, ground foods are offered at school breakfast and lunch.
• Rachael receives tube-feeding at lunchtime. On days that the school nurse is not available to administer the tube feeding, a public health nurse comes to school.

The need for a special food or food pattern must be documented by a medical authority. This documentation should explain how the chronic condition affects the child’s food pattern, explain the changes necessary, and suggest meal modifications (for example, sample substitutions).

Nutrition Therapy Goals

With collaboration between the family, the health care provider and the child’s school, teachers, and therapists, nutrition therapy goals can be incorporated into a child’s educational plan as well. Examples of children with nutrition therapy goals incorporated into an educational plan:
• Samantha, a 2-year old with Down syndrome (trisomy 21), has oral-motor problems that interfere with feeding. The IFSP states that, in addition to the speech therapy she receives at her Early Intervention program, part of each therapy session address feeding skills.

• Evan is a 14-year old with type 1 diabetes who attends the state school for the deaf and hearing-impaired. His IEP includes a goal for learning carbohydrate counting. His teacher, the school nurse, and the RD coordinate the learning objectives.

• Sylvia has autism, is in a developmental preschool, and has a nutrition goal incorporated into her IEP. During lunchtime, behavior strategies are used to address feeding behaviors; the current goal is that Sylvia will sit at the table for 10 minutes.

Incorporating these types of goals into a child’s IEP requires cooperation and collaboration between the child’s family, school, and health care providers. Working together to incorporate realistic, workable goals and objectives is the most effective approach.
Section 3: Other Resources

This section provides a list of some resources related to children with special health care needs. It is by no means an exhaustive list.

The Arc of America http://www.thearc.org/ is a national association addressing mental retardation and related developmental disabilities through education, research, and advocacy.

The Center for Children with Special Needs http://www.chscn.org provides information and resources for families and health care providers.

Family Village http://www.familyvillage.wisc.edu/index.html is directed at persons with disabilities, their families, and service and support providers. Resources include information about specific diagnoses, adaptive technology and products, recreation, and educational opportunities.

Exceptional Parent magazine http://www.eparent.com is written for families of children with special health care needs and provides information about health care, resources, and medical conditions. The extensive website provides additional information.

Family Voices http://www.familyvoices.org is a national clearinghouse for information about children with special health care needs.

The National Center for Children and Youth with Disabilities http://www.nichcy.org is an information and referral service for families with children with disabilities and for professionals who work with children with disabilities.

National Organization of Rare Diseases (NORD) http://www.rarediseases.org is a clearinghouse for information about rare disorders.

Evaluating websites

There are many websites with good information—there are also many websites with inaccurate information.

It is important to evaluate all information. Use the tips on the next slide and common sense to evaluate all information from the web. These tips can also be provided to families as they look for health information on the Internet.

As you review a site, ask the following questions:

- Are the authors’ names and credentials listed? Does the site describe the authors’ qualifications?
- Can you contact the authors for more information if you have questions?
- Where does the information come from? Are these sources reliable?
- What is the purpose of the website? (Possible purposes include informing the public, selling a product, gathering information.)
- Are sponsors listed? (Maintaining a website costs money—who is paying to maintain the site you’re using?)
- Is the information up-to-date? (Good websites list the “date last revised” on each page.)
Section 4: Intervention Strategies

This section “walks” you through the decision-making process. Two examples of children with special health care needs who utilize several community services and programs are presented.

Scenario 1: Mary

Mary is a 2 ½-year old who was born prematurely and has significant developmental delays.

She receives speech, occupational, and physical therapy at the local early intervention program. Her IFSP includes goals for feeding skills, and the RD who works with Mary communicates regularly with her therapists.

Mary is enrolled in the state Children with Special Health Care Needs program. She is also eligible for Medicaid, but the private insurance policy that is part of her father’s benefits package provides the primary coverage.

The decision is made to place a feeding tube, because Mary’s rate of weight gain has slowed considerably and her therapists do not feel that her oral intake will increase significantly in the near future.

Recommendations for Mary’s tube feeding are made, and the prescription is sent to a home infusion company in Mary’s community.

Although many services, including the tubing and equipment needed for Mary’s tube feeding, are covered by her father’s insurance company, Mary’s enteral formula is not. Which of the following services will help pay for Mary’s formula?

a. early intervention program
b. state children with special health care needs (title V program)
c. Medicaid
d. Head Start

The correct response is c. Medicaid.

Benefits vary between states, but in Mary’s case, Medicaid provided secondary coverage, reimbursing for services that were not covered by the primary payer.

In Mary’s state, children under age 5 years who are eligible for the Children with Special Health Care Needs (Title V) program are also eligible for WIC. The WIC program in Mary’s state provides vouchers for a standard pediatric formula (the formula that is prescribed for Mary) when it is needed.

Mary’s enteral supplies and formula are paid for by several resources:
- Supplies and equipment are covered by her primary, private insurance
- The majority of her formula is paid for by the WIC program
- The portion of the formula not provided by WIC is paid for by Medicaid

When Mary is no longer eligible for WIC, Medicaid will provide reimbursement for all of Mary’s formula.
Scenario 2: Christopher

Christopher is a 3-year, 3-month old who has autism.

Which of the following services might he be eligible for? Click all that apply. Then click the "Submit" button to see the correct responses.

- early intervention
- WIC
- Medicaid
- developmental preschool

The correct responses were WIC, Medicaid, and developmental preschool. Christopher is not eligible for early intervention services since he is over age 3 years.

Christopher has feeding problems and has been admitted to the local hospital for failure-to-thrive. The community RD sees Christopher in clinic.

He receives the following services:
- WIC
- Medicaid
- Developmental preschool

Feeding skills are included in Christopher’s IEP, and he receives 2 speech-therapy sessions each week.

His family and therapists feel that Christopher would benefit from group feeding-therapy sessions. The school district is not able to provide this, however. Which service might provide reimbursement for group feeding therapy?

a. WIC
b. Medicaid
c. both of the above
d. none of the above

The correct response is b. Medicaid. In some states, Medicaid will provide reimbursement for feeding therapy.

Fortunately, a feeding therapy group is available in Christopher’s community. Medicaid provides reimbursement for these sessions.

Christopher’s family keeps records from his feeding therapy sessions in a notebook. This notebook is a communication tool between the family, Christopher’s therapists, and his health care providers.
Post Test

QUESTION 1

A three-year old with complex medical needs requires a gastrostomy tube to meet her nutrient needs. Her family’s income is about 180% of the federal poverty level. This child might be eligible for services from which of the following programs?

a. WIC  
   b. State Title V Program  
   c. Medicaid/EPsDT  
   d. all of the above

QUESTION 2

Which of the following programs receives funding as a result of the federal IDEA, Part C, but is administered differently between states and jurisdictions?

a. Early intervention  
   b. State Title V Programs  
   c. Medicaid/EPsDT  
   d. SCHIP

QUESTION 3

Emily’s mother has read that a vegetarian diet may be protective against heart disease. Since there is a history of heart disease in Emily’s family, she requests a 504 Accommodation Plan directing the school to provide a vegetarian lunch to Emily.

Is this an appropriate nutrition therapy goal?

a. yes  
   b. no

QUESTION 4

The correct response to the previous question was No, requesting a vegetarian food pattern because of a family history of heart disease is not an appropriate nutrition therapy goal.

Why is the goal inappropriate?

a. Because there is no evidence to support the protective effect of a vegetarian diet against heart disease.  
   b. Because a family history of heart disease is not a documented health impairment or chronic condition and doesn’t interfere with participation in school activities.  
   c. Because Emily is not in a special education program, so there is no IEP.  
   d. None of the above.
QUESTION 5

Mark is a 5-year old with oral-motor problems that require that he eat ground or pureed foods. He is in a special education program. Which of the following plans should include the meal accommodation request?

a. 504 Accommodation Plan  
b. IEP (Individualized Education Plan)  
c. IFSP (Individualized Family Service Plan)  
d. none of the above

QUESTION 6

Martin is a 10-year old with a complex medical history. He has nonprogressive encephalopathy which has resulted in seizures, and intermittent hypotonia and hypertonia. Martin receives monthly SSI payments.

Which of the following resources is most likely utilized by Martin and his family?

a. Medicaid  
b. WIC  
c. SCHIP  
d. none of the above

QUESTION 7

Martin also has problems with feeding. He has a gastrostomy tube to ensure that his fluid and nutrient needs are met. He receives 2 cans of formula at home, and one can at school. Martin’s occupational therapist has been working with Martin and feeding skills.

Martin’s mother would like to incorporate nutrition goals into his IEP. She feels that the school is addressing nutrition-related issues, but would like it formally included in his educational plan. Which of the following statements is true?

a. Only the need for tube feedings at school can be included in the IEP.  
b. Only the feeding skills can be incorporated into the IEP; the need for tube feeding requires a 504 Accommodation Plan.  
c. Both the feeding skills and the need for tube feedings can be incorporated into the IEP.  
d. Neither the feeding skills nor the need for tube feedings should be incorporated into the IEP, since the school is already addressing those issues.

QUESTION 8

The cost of Martin’s enteral supplies are covered by Medicaid, and Medicaid also covers the cost of two-thirds of his formula. Which of the following resources might cover the cost of the remaining one-third in some states?
a. Commodity Supplemental Food Program
b. State Title V Program
c. IDEA, Part C
d. Head Start
For More Information About Integrating Community Services and Programs


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


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

