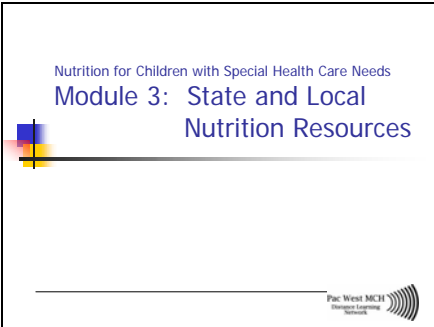


Pacific West Distance Learning Network
Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 3: State and Local Nutrition Resources
Speaker Notes

1



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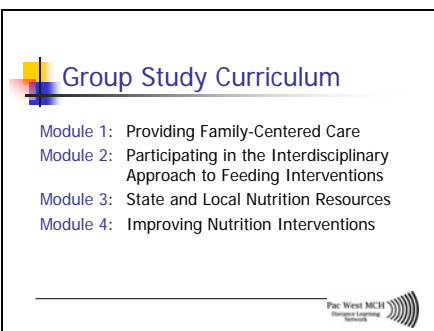


All of these materials are available free-of-charge on the website listed.

Participants may also be interested in the self-study curriculum.

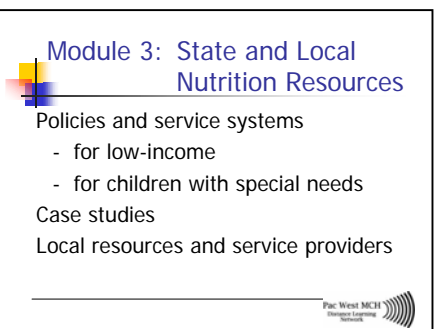
There may be a charge for continuing education credit.

3



These four modules are available as group-study topics for in-services and other meetings. The material in these modules is best learned through an interactive process between the group leader and amongst the group members. A Leaders' guide, PowerPoint presentations, handouts and video segments are available free-of-charge.

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The first part of this presentation 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. Part of the group process


will be discovering what these programs and services are called in your area and how to access them. At the end of the presentation there are some case studies and opportunities to discuss resources available in your local area.

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Learning Objectives

After completing the module, participants will have the knowledge and skills to:


- Identify key agencies and health professionals involved in the support and provision of nutrition services
- Access funding sources for nutrition services for children with special health care needs



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Video - Jesus

- What types of nutrition services does Jesus need now?
 - What service programs could provide the services?
- What types of nutrition services did Jesus need as an infant (early failure-to-thrive)?
 - What service programs could provide the services?




This is an optional activity which provides an example of a child with multiple needs, not just nutrition needs, and a common reference point for further discussion. As the video is played, listen for times in the family story when the services of a nutritionist might be helpful.

When the video is over, ask the group what service programs they know of that could have provided services for this child and family.

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Programs for Low-Income

- Medicaid
- EPSDT
- SCHIP
- WIC
- Head Start
- Food Assistance




Now we are going to give some information about programs that potentially can provide nutrition information or services to children with special needs. The first type of programs are those that are designed to provide a nutrition safety net for families with low income. Some of these programs provide additional services or benefits to children with special needs.

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Medicaid

- Title XIX of the Social Security Act
- Medical care for eligible families with low incomes
- Funded by federal and state governments
- Eligibility, administration, and services vary between states...in many states, most children with special needs are eligible
- Nutrition services covered vary from state-to-state
 - ? nutrition services
 - ? supplements or enteral supplies
 - ? services by feeding team members




What is the name of this program in your area?

Eligibility in many states is related to SSI eligibility and therefore children with special needs may be eligible depending on their diagnosis, as well as their income.

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Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)

- Component of the Medicaid program for persons under 21 years of age
- Medicaid eligibility = EPSDT eligibility
- Guidelines include screening for nutritional problems and services to treat conditions identified by the screening



Does this program have a different name in your state?


Do you know if nutrition services are being reimbursed through this program in your area?

EPSDT is designed to provide additional treatment/benefits for children with identified needs, and this can include nutrition services.

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State Children's Health Insurance Program (SCHIP)

- Helps states to expand Medicaid eligibility
- Eligibility, administration, and services vary between states that participate in SCHIP




What is this program called in your state?
 What are the eligibility criteria in your state?
 How can nutrition services be accessed by individuals eligible for SCHIP?

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Supplemental Nutrition Program for Women, Infants, and Children (WIC)

- Funded by the Food and Nutrition Service, USDA
- Nutrition education and counseling, health screening, referrals for other services, monthly food packages/vouchers, checks for formula




What services does WIC provide in your community?
 Are WIC RDs able provide additional services to children with special health care needs?
 Some RDs have found ways to provide care for CSHCN, including collaborating with the providers at specialty clinics (for example, combining growth & intake information and developing a nutrition care plan together).

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WIC – continued

- Eligibility varies between states and counties:
 - Pregnant women
 - Women with breastfeeding infant up to age 1 year
 - Children up to age 5 years
 - At nutritional risk
 - Incomes \leq 185% of the federal poverty level
 - Children who are eligible for Medicaid
- Some agencies:
 - Provide f/u services to CSHCN and bill Medicaid
 - Provide specialized nutritional formulas




Nutrition screening is one component of the head start program. Nutrition education is another.

Usually if a special nutritional need is identified by the Head Start nutritionist, the child is referred back to their primary care provider to obtain additional nutrition services.

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Head Start / Early Head Start

- Overall goal: promoting school readiness for children from low-income families
- Provides social health services (including medical, dental and nutrition screening)
- Federal law reserves 10% of enrollment slots for children with disabilities



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Food Assistance Programs

- Commodity Supplemental Food Program (USDA)
- Food Stamp Program (USDA)
- The Emergency Food Assistance Program (USDA)
- Child and Adult Care Food Program (CACFP)



Commodity Supplemental Food Program
 - provides canned or packaged foods to pregnant/postpartum and BF women and children with incomes <185% of federal poverty level

Food Stamp Program
 - provides coupons for the purchase of foods to families who meet income eligibility requirements

Emergency Food Assistance 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

- provides USDA-supported meal reimbursement for childcare providers with low-income eligible children

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Programs for special needs

- Title V - Children with Special Needs
- State Disability Programs
- Early Intervention
- Education (Special Education IEP and Medical Need 504 plan)
- SSI



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Title V/CSHCN Program

- Administered to US states and jurisdictions by MCHB/HRSA
- Federal-State partnerships to develop systems of service for MCH, including CSHCN
- Eligibility and services vary between states:
 - Provide direct service or pay for services
 - Assure services—safety net when services are not provided by another source




What is the Title V program called in your state?
 What nutrition services (if any) does Title V provide in your state?
 What type of services include nutrition services – specialty clinics (tertiary care)? community-based services? centralized or regionalized services?
 Center-based or home visits?

Are there criteria for providers? (e.g. paneling in California)?

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State Disability Program

- Administration on developmental disabilities (federal)
- States usually provide additional funds, state disability council
- Administration may be housed in separate office at state level, or combined with MCH programs
- Usually covers birth-death special needs, programs vary widely in services provided



Is there a state disability office in your state? What is it called? Is there a different name for the service system providing for people with disabilities?


This program is often responsible for state-funded programs (hospitals/institutions, group homes, residential and day treatment programs) for people with disabilities. Are you aware of, or familiar with, the nutrition services provided to individuals in these

programs? Do you know what services are provided in the community through this program?

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Early Intervention

- Funding mandated by IDEA, Part C (federal)
- Provides assessment and intervention services (including nutrition) for infants and children 0-3 years old with developmental delay or other special health care needs, or at risk for delays
- Services guided by interagency coordinating council (ICC) - state and local
- May be administered through school system or disability services system



Services include audiology, home visits, nutrition, OT, PT, family counseling, vision services, and others.


What is this program called in your state?

What agency provides these services?

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Educational System

- Federal regulations require that the public school system accommodate children with special health care needs...including nutrition-related issues that support learning/school attendance:
 - Individuals with Disabilities in Education Act (IDEA) (1990)
 - Section 504 of the Rehabilitation Act of 1973
 - Americans with Disabilities Act (ADA) of 1990
- Nutrition goals can be incorporated into a child's educational plan



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

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Educational System

- IFSP (Individualized Family Service Plan)
 - For 0-3 year olds in Early Intervention programs
- IEP (Individualized Education Plan)
 - For 3-21 year olds who receive Special Education
- Interdisciplinary agreements between family, teachers, and therapists
- Revised at least once per year
- Specify how each goal to be accomplished



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



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

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.

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Educational System: Michael's IEP

- Given a cup filled ¼ to ½ full, Michael will take in the proper amount of liquid and return the cup without spilling in 4 out of 5 opportunities by September 15.
- Given a developmentally-appropriate meal/snack, Michael will remain seated during the meal/snack time (or until excused) in 4 out of 5 opportunities by September 15.

Michael is in a special education classroom. He has delayed oral-motor skills.

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

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.

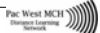
Educational System: 504 Plan

504 Accommodation plan

- For a child who does not receive special education services, but who needs special, health-related services during the school day

Example of nutrition services in a 504 Plan:

- 11-year old with type 1 diabetes
- 504 Plan: Cheryl will be permitted to eat a mid-morning and afternoon snack (brought from home) during recess



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.


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. 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).

Supplemental Security Income (SSI)


- Administered by the social security administration
- Monthly payment for some CSHCN (dependent upon family income)
- Often “gateway” to other services... eligibility for SSI = eligibility for WIC, Medicaid, and/or title V program



SSI services usually consist of a cash benefit (monthly payments) for the child’s care, as well as providing eligibility for other programs (e.g. Medicaid).

Case Study 1: Sarah

- 22 month old, new to the community
- Born at 32 weeks, had BPD
- Eats soft table foods, some junior meats
- Lost 1 pound over past 6 months, length continues “in channel”
- From low-income family with few resources
- Enrolled in early intervention program; Staff is concerned re: lack of weight gain, but no RD with program




Problem: Toddler with growth failure who requires a special pediatric formula

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Case Study 1: Sarah

What services might be available to Sarah?

- Medical care?
- Food/formula?
- Nutrition services?
- Care coordination?



(If there is time and the group is large, encourage participants to turn to their neighbor and discuss these questions briefly. Otherwise, the group leader can discuss these issues with the whole group.)


A variety of local resources exist for low-income children with special health care needs. Early intervention programs provide care coordination for families and can assist with the referral process as well. All programs need to be coordinated to provide continuity of care. The IFSP is an excellent tool to use to assist families and providers to obtain services, target goals for a child and to monitor progress. If Sarah does not have a “medical home”, obtaining a primary care provider can become an IFSP goal.

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Case Study 1: Sarah

What services might be available to Sarah?

- Community referrals:
 - Medicaid
 - Title V / Children with Special Health Care Needs
- WIC (services, specialized food package)
- Need for formula? ...WIC, Other funding source? Rx from PCP, EI coordinate appointments?
- Coordinate with WIC RD to develop goals/outcomes and objectives for IFSP




Medical care: **Medicaid, Title V program**
 Food formula: **WIC, Title V program (may need prescription from primary care provider)**
 Nutrition services: **WIC, Early intervention? Specialty clinic if urban (Title V)**
 Care coordination: **Early intervention, state disability program, Title V program, “medical home” = primary care provider**

The medical home/primary care provider needs to know about and address Sarah’s recent weight loss and coordinate nutrition follow up.

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Case Study 2: Alex

- 8 year old with spina bifida and learning disabilities; in special education program
- Short stature, gained 10 pounds in last 6 mo
- Has outgrown wheelchair
- Participates in school lunch and breakfast
- Followed by RD in Title V Program/ Spina Bifida Clinic
- Has Medicaid benefits




Problem: Overweight child in special education requiring diet modifications and new equipment.

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Case Study 2: Alex

What services might be available for Alex?


- Medical care?
- Food/formula?
- Nutrition services?
- Care coordination?



(If time, and the group is large, encourage participants to turn to their neighbor and discuss these questions briefly. Otherwise, the group leader can discuss these issues with the whole group.)

The goal of weight maintenance is appropriate for a growing child. Children with spina bifida usually have a low metabolic rate and need energy-controlled diets to prevent obesity, but their diets must be planned so that the energy restrictions do not interfere with linear growth. For the best outcome, meal modifications and activity schedule should be coordinated between the home and school. The IEP is a good planning tool to use to facilitate coordination and should include any specific activities and goals for the school program.

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 **Case Study 2: Alex**

What services might be available for Alex?

- School nutrition services to provide appropriate meals...e.g., ↓ Energy to maintain weight and support continued linear growth
- IEP could include physical activity goal to include adaptive PE program, increasing exercise
- Referral to PT for evaluation for new wheelchair
- Coordination between school nutrition manager, teachers, therapists, RD at Spina bifida clinic

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Medical care: **Medicaid, Title V program, private insurance?**


Food formula: **Title V program (may need prescription from primary care provider), Medicaid**

Nutrition services: **Specialty clinic if urban (Title V)**

Care coordination: **State disability program, Title V program, “medical home” = primary care provider**

The medical home/primary care provider needs to know about and the goal of weight loss/maintenance and coordinate nutrition follow up.

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 **Further thought...**


- What is one resource discussed today that you were not previously aware of?
- How have you collaborated with other agencies to provide nutrition services?
- Think of one instance where access to one of the services discussed today would have improved a nutrition intervention.

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Are there any other services that you know about now that could have helped Jesus and his family (from the videoclip)?

Other questions?

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 **Conclusion**

- National resources (handout- websites)
- Local resources
- Post-test and evaluation

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Review “Resource” handout

Review local resource handout, if you have prepared one, or discuss and generate a list of local resources.

Ask the participants to complete the post-test and evaluation form and turn them in to receive their certificate of completion.