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ABSTRACT

This guide was developed to assist families and service providers in Connecticut with nutrition services for infants and toddlers with disabilities. Individual sections provide information about the following topics: laws and regulations related to nutrition services; eligibility for the Connecticut Birth to Three System and nutrition; nutrition specialists; the importance of nutrition in overall development; parents' perspective on nutrition; nutrition screening; nutrition assessments; recommended dietary intake; feeding; lactation for the infant with special needs; nutrition care for premature and low birth weight infants; alternative and complementary medicine; and transition from Birth to Three services. Appendices include the mission statements of the Connecticut Birth to Three System, results of a survey of nutrition services to which 34 Connecticut Birth to Three programs responded, a glossary, a list of resources, a Birth to Three nutrition screening questionnaire, and a description of various formulas for infants and toddlers. (Contains 63 references.) (DB)

Service Guideline 6

Nutrition

Intervention guidance for service providers and families

January, 2000

Connecticut Birth to Three System

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PREFACE

The Connecticut Birth to Three System provides comprehensive services to children with a wide range of disabilities and delays and their families through 38 approved programs. See Appendix One for the Mission. In the spring of 1998, the Connecticut Birth to Three System surveyed the programs regarding how they provide nutrition services to children, and their needs, if any, in the area of nutrition. Of the 34 programs that responded, 24 felt they could use some additional information or training on this topic. See Appendix Two for complete survey results.

In an effort to address some of the identified needs for information and to clarify the Connecticut Birth to Three System's use of nutrition services, a task force was convened to develop this guideline. The task force brought together representative stakeholders in the Birth to Three System including parents, providers, nutrition professionals, the Director of Child Nutrition Programs at the State Department of Education, a representative from the State Interagency Coordinating Council (ICC), and a Birth to Three System administrator. The task force identified the following goals for the Nutrition Guidelines:

1. Clarify federal law and regulations regarding nutrition services under the Individuals with Disabilities Education Act (IDEA);
2. Increase Birth to Three staff's awareness and knowledge of the important role nutrition plays on the overall physical and emotional development of the child;
3. Provide information on talking with families about nutrition, feeding, and the cultural issues which are inherent in these topics;
4. Increase knowledge of screening and assessment tools and measures that can be integrated into the overall assessment of a child in the Birth to Three System;
5. Provide information on culturally sensitive resources for assessing and meeting children's nutritional needs, including the limitations of some resources;
6. Provide information and suggested resources for training staff and families on nutritional issues; and
7. Assist Birth to Three staff to: a) know when to involve a nutrition specialist in a child's assessment or service plan; b) understand the role of a nutrition specialist on the team; and c) realize the importance of continuity of care during transitional times in the child's life.

The task force developed a draft of this document which was then distributed for comment to the larger Birth to Three community including parents, Local Interagency Coordinating Councils (LICCs), the State Interagency Coordinating Council (ICC), Birth to Three providers, the Medical Advisory Committee, and nutrition professionals from Connecticut and other states. A glossary is included to assist the reader. See Appendix Three.

Note: In this document, the term nutrition specialist will be used to refer to the professional who meets the required credentials and certifications of a Nutritionist, Registered Dietitian, Certified Dietician/Nutritionist, or Certified Nutrition Specialist.

LAWS AND REGULATIONS THAT RELATE TO NUTRITION SERVICES

The Connecticut Birth to Three System operates in accordance with Part C of the Individuals with Disabilities Education Act (IDEA). In the statute, the list of early intervention services is as follows:

Sec. 1432 (4) (E) Definitions
Early Intervention Services include –

I. Family training, counseling and home visits;
II. Special instruction;
III. Speech-language pathology and audiological services;
IV. Occupational therapy;
V. Physical therapy;
VI. Service coordination;
VII. Medical services only for diagnostic or evaluation purposes;
VIII. Early identification, screening, and assessment services;
IX. Health services necessary to enable the infant or toddler to benefit from other early intervention services;
X. Social work services;
XI. Vision services;
XII. Assistive technology devices and services;
XIII. Transportation; and
XIV. Related costs that are necessary to enable an infant or toddler's family to receive another service described in this paragraph.

Nutritionists are named in Section 1432 (4) (F) of the statute, which lists the personnel qualified to provide early intervention services.

Nutrition services are included as a type of early intervention service in Section 303.12(d)(7) of the IDEA regulations and are defined as follows:

(i) Conducting individual assessments in--
  (A) Nutritional history and dietary intake;
  (B) Anthropometric, biochemical, and clinical variables;
  (C) Feeding skills and feeding problems; and
  (D) Food habits and food preferences;
(ii) Developing and monitoring appropriate plans to address the nutritional needs of children eligible under this part, based on the findings in paragraph (d)(7)(i) of this section; and
(iii) Making referrals to appropriate community resources to carry out nutrition goals.

Therefore, while not explicitly included in the statute, it is the intent of IDEA, through its regulations, that nutrition services that are designed to meet the developmental needs of an eligible infant or toddler should be provided through the Birth to Three System.

ELIGIBILITY FOR THE CONNECTICUT BIRTH TO THREE SYSTEM AND NUTRITION

The Connecticut Birth to Three System is a state and federally funded entitlement program for families whose children are under the age of three and have disabilities or significant developmental delays. In Connecticut regulations 17a-248-1 and 17a-248-3, children under age three are eligible to receive services from the Connecticut Birth to Three System if they:

- have been diagnosed as having a physical or mental condition, that has a high probability of resulting in a significant developmental delay; or
- are experiencing a significant developmental delay as measured with standardized instruments administered by a multidisciplinary team.

Children are not eligible for services based on issues related to their nutrition status only, but may be eligible due to a medical condition or a significant developmental delay with which nutritional needs are associated.

Once a child is determined eligible, an assessment of the child and of the family's priorities, concerns, and resources is completed. This assessment process helps the family identify what outcomes will be addressed in the Individualized Family Service Plan (IFSP) and the supports necessary to achieve these outcomes. During the assessment, information is gathered by Birth to Three staff related to the child's nutritional status. If the nutritional needs are related to the child's ability to make developmental progress, then the provision of appropriate nutritional supports or services will be the responsibility of the child's Birth to Three program and will be included as early intervention services in the IFSP.

Some children are eligible for Birth to Three services, yet have nutritional needs that are medical in nature and therefore not the responsibility of the Birth to Three program to provide. The following three scenarios are offered to clarify when nutrition services are a Birth to Three responsibility and when they are a medical service that falls outside the realm of the Birth to Three System:

Scenario 1 – Child enrolled in the Birth to Three System and receiving nutrition services from her Birth to Three program

Brenda was born prematurely and had several health complications at birth. She was eligible for the Connecticut Birth to Three System based on her prematurity and significant delays in development. Brenda's growth was a constant concern for her doctors and her interventionists who were addressing her ability to perform age appropriate motor tasks as well as support her family in appropriate feeding techniques. Her Birth to Three program added their nutrition specialist to the team and she completed a nutritional assessment. As a result of this assessment, an IFSP was written, in consultation with Brenda's pediatrician, which included having the nutrition specialist consult with the parent at specific intervals and reassess Brenda before her next annual review. The family was also given a feeding plan which identified appropriate foods and feeding schedules for Brenda. As Brenda grew in weight, the nutrition specialist continued as part of the team to assess her changing nutritional needs and monitor her progress.

Scenario 2 – Child with need for nutrition services but not eligible for Birth to Three services

John was born with a heart defect, which required hospitalization and surgery after birth. While in the hospital, John required a feeding tube to receive proper nutrition. When he came home after the surgery, his mother had difficulty with the transition to oral feedings. John was referred to the Birth to Three System for assistance with oral motor skills and feeding issues. John was evaluated and found not eligible for the Birth to Three System because he was at or close to age level in all areas of his development. The parent was referred to the Children With Special Health Care Needs program where he was able to receive therapy services to support his parents' efforts to move him away from the tube feedings and onto oral feedings. The input of a nutrition specialist was also available to the family through this program.

Scenario 3 – Child in the Birth to Three System with nutrition services received as part of medical services

Kevin is a two-year-old child with a seizure disorder and significant developmental delays. He has been receiving Birth to Three services since he was one. After his last visit to the doctor, Kevin's family decided to institute a Ketogenic diet to help to control Kevin's seizures. In order to begin this diet, Kevin would have an initial hospitalization for medical tests and the a strict diet would be developed. Ongoing tests would then need to be completed to assure that Kevin was in a state of Ketosis.

These other services were listed on Kevin's IFSP in Section VI under "Other Child Related Services". The Birth to Three program staff, while not directly involved with the treatment, kept in touch with Kevin's doctors and nutrition specialist throughout this process. Their goal was to know Kevin's progress and to understand the requirements of this diet. By understanding the diet the Birth to Three staff were able to assist Kevin's family to adjust to the impact the diet was having on their daily routines.

NUTRITION SPECIALISTS

Who is a Nutrition Specialist?

When seeking the services of a Nutrition Specialist the following definitions of credentials help to identify an expert in the field of nutrition:

R.D. (Registered Dietitian)*- This credential is given by the Commission on Dietetic Registration, a private agency. R.D.s have at least a bachelor's degree from an accredited college/university, have completed supervised work experience, have passed a national exam, and earned continuing education credits. The R.D. is recognized by most healthcare facilities as the standard for nutrition practice.

C.D.N. (Certified Dietitian-Nutritionist) and L.D. (Licensed Dietitian)*- Connecticut recommends a C.D.N. credential for anyone practicing nutrition in this state. C.D.N.s must meet strict requirements that are equivalent to R.D. requirements. Insurance companies may require the C.D.N. credential in order to receive reimbursement for services.

C.N.S. (Certified Nutrition Specialist) - This credential is given by the Certification Board for Nutrition Specialists and recipients are generally members of the American College of Nutrition, a respected organization of nutrition scientists. Recipients have advanced degrees in nutrition or a closely related area from an accredited program, have work experience, earn continuing education credits, and repeat an exam every ten years.

Connecticut Birth to Three System Personnel Standards

Category: Dietitian-Nutritionist (certified)

Entry Degree: Registered Dietitian or Masters Degree or Ph.D. with major course of study in nutrition or dietetics

Licensure/Certification: Department of Public Health Certification required under §20-206 Connecticut General Statutes

Additional Supervision Required: None

Job Responsibilities: Conducts nutrition assessments, provides medical nutrition therapy, participates in IFSP development and implementation, monitors outcomes as part of a transdisciplinary team, and provides direct or consultative services to families and professionals. Can conduct evaluations and annual assessments and can assume service coordination responsibilities after successful completion of service coordination training.

*Dietitians can also become board certified in the area of Pediatric Nutrition. Certification is granted once applicants can document their completion of the required practice experience, and after they have successfully completed a written examination in the specialty area.

Including the Nutrition Specialist on the Birth to Three Team

Nutrition specialists can play an active role as part of the Birth to Three team.

In the IFSP process, the nutrition specialist:

- participates in developmental evaluations and the IFSP process;
- conducts individual assessments in--
  - nutritional history and dietary intake;
  - anthropometric, biochemical, and clinical variables;
  - feeding skills and feeding problems; and
  - food habits and food preferences;
- develops and monitors appropriate plans to address the nutritional needs of children;
- monitors child's nutrition status and re-evaluates care plan as needed;
- initiates contacts with other nutrition services needed by the child;
- provides direct nutrition counseling services (in the home, or by phone contact as appropriate);
- identifies service gaps based on identified needs;
- provides service coordination for nutrition-intensive cases including ongoing contact with physicians, as appropriate.

In providing education, training, and support services for parents and staff, the nutrition specialist:

- identifies nutrition training needs of parents and staff;
- conducts parent support groups on feeding;
- conducts staff in-services on growth, nutrition, and feeding;
- participates in child/parent groups and other staff activities.

In locating community nutrition services and referral for follow-up, the nutrition specialist:

- identifies community nutrition service providers;
- establishes communication with other nutrition care providers;
- refers family for follow-up as part of the transition plan from Birth to Three services;
- provides education and training on nutritional needs of children with special needs to staff, parents, and community service providers.

Family or child nutrition concerns should be written in the Individualized Family Service Plan (IFSP). Outcomes or services to address these concerns could include assessments and intervention by a nutrition specialist. If a child is receiving nutritional support from outside of the Birth to Three program, this information should be included in the plan and, with parent permission, ongoing communication between the Birth to Three program staff and community staff arranged. If appropriate, and if the parent chooses, a Birth to Three nutrition specialist can act as the family's service coordinator. To do this they must complete the Connecticut Birth to Three System's required training.

THE IMPORTANCE OF NUTRITION IN OVERALL DEVELOPMENT

Adequate nutrition is essential to a child's growth and development from conception to adolescence. During the first year of life, rapid growth occurs:

- A baby's weight doubles from three to six months and triples by nine to twelve months;
- He or she grows almost ten inches during the first year of life and an additional 4.75 inches by the second year;
- By twelve months, the brain has increased its weight three times;
- By the second year of life, a baby's head circumference reaches eighty percent of its adult size.

Calorie, vitamin, protein, and mineral intake need to be sufficient in order to ensure appropriate growth in a child. The possible effects of inadequate nutrition and feeding are:

Areas of Development		*Consequences of Inadequate Nutrition*
○ Brain development	⇒	Impaired cognitive and neurological development
○ Physical development/growth	⇒	Motor delays due to inadequate muscle/ bone development
○ Social/emotional development	⇒	Poor feeding behavior impairing readiness for transition to age appropriate food stages
	⇒	Lack of positive mealtime experience
○ Oral motor development	⇒	Poor feeding skills leading to inadequate intake
	⇒	Potential language delay
○ Health and motor development	⇒	Lowered resistance to infection
	⇒	Impaired dental status
	⇒	PICA (eating of non-food items)
	⇒	Reduced energy and listlessness due to poor intake
	⇒	Problems with bowel function

In order to address the complex and varied nutritional needs of children enrolled in the Birth to Three System, the involvement of a nutrition specialist on a multidisciplinary team made up of family and professionals (occupational therapist, physical therapist, speech and language therapist, nurse, social worker, physician, developmental therapist, child care provider, or behavioral psychologist) can contribute to the early identification of nutritional problems which may prevent a child from reaching his or her growth potential. Nutrition specialists provide nutrition counseling and education taking into consideration cultural background, food preferences, food availability, food quality, food attitudes and beliefs, and environmental factors that influence dietary change.

PARENTS' PERSPECTIVES ON NUTRITION

Parents and caregivers face the day to day concerns of feeding their child, and they need the professionals that come into contact with their child to understand that nutrition and feeding issues permeate all aspects of family structure because they touch on social, emotional, and cultural areas. As illustrated by the following points:

- In our earliest moments in life, as newborns, we enjoy feeding not only for nutrition but also for the closeness, comfort, and security it provides;
- Feeding is a part of life 24 hours a day, 7 days a week;
- Parents associate feeding with love; culturally it is important to offer food;
- Eating and entertaining are looked upon as a social time to gather with friends and family;
- Throughout the year, holidays and celebrations focus on certain foods such as a Thanksgiving turkey or a birthday cake as a part of the celebration;
- Parents can have a difficult time accessing nutritional or feeding supports in either hospital-based settings or community-based settings;
- Recommendations for specialized foods and formulas can be costly to the family and may require creative payment sources;
- Feeding is not always a pleasant experience for the child and different methods to encourage eating may be required;
- When children have specialized diets, the family may need suggestions for introducing or substituting certain foods.

When it comes to these feeding and nutritional issues, many people may be involved: mother, father, siblings, grandparents, daycare providers, therapists, community support personnel, and others. A nutrition specialist and the Birth to Three team must work with the family to develop a realistic plan that can be carried out by all parties, considering such issues as plan implementation, parent participation, cultural values, and supports for the family when things do not go as planned.

Parents who have been presented with a diagnosis or concern about their child may be experiencing many emotional responses such as anxiety, depression, anger, guilt, and fear for the future. It is important for early interventionists to establish a comfortable communication network by assuring a parent that all questions are acceptable, supporting parents to speak up regularly, and repeating or reviewing information with parents.

CULTURAL DIVERSITY AND NUTRITION

Professionals working with families to meet their child's unique nutritional needs should be aware of their own biases toward other cultures. An effort to become knowledgeable about other cultures and sensitive to practices, lifestyles, values, and beliefs around food and nutrition is the beginning of a healthy parent and professional relationship.

Embedded in the Mission of the Connecticut Birth to Three System is the assurance that services and supports are built upon mutual respect and choice. The elaboration of that tenet supports the idea that nutrition specialists and team members working with children and families can show their sensitivities to families by listening to the parents' views on nutrition and integrating those views into the plan for intervention. A partnership must be formed to support families in a collaborative manner so that the plan is safe and healthy for the child.

The mission of the Connecticut Birth to Three System is to strengthen the capacity of Connecticut's families to meet the developmental and health-related needs of their infants and toddlers who have delays or disabilities. The system will ensure that all families have equal access to a coordinated program of comprehensive services and supports that:

- *foster collaborative partnerships*
- *are family centered*
- *occur in natural settings*
- *recognize current best practices in early intervention*
- *are built upon mutual respect and choice*

Respect and Choice: Recognition and inclusion of the knowledge, beliefs, aspirations, culture and preferences of families should be a cornerstone of all planning and delivery of supports and services. Professionals should openly share roles and assist one another in expanding competencies. Teamwork, wherein the family is an important participant, should guide all decisions. Families should be provided with opportunities to choose programs whenever possible. Their satisfaction with services should be an important factor in selecting and evaluating providers of support.

The following information, taken from "Suggestions for Guidelines and Using Food to Create Common Ground" offers suggestions to providers as they begin to speak with families from diverse cultural backgrounds about nutritional issues, and about foods common to their daily diets.

Families make food choices depending on:

1. Food cost and accessibility;
2. Traditional family eating patterns resulting from cultural values;

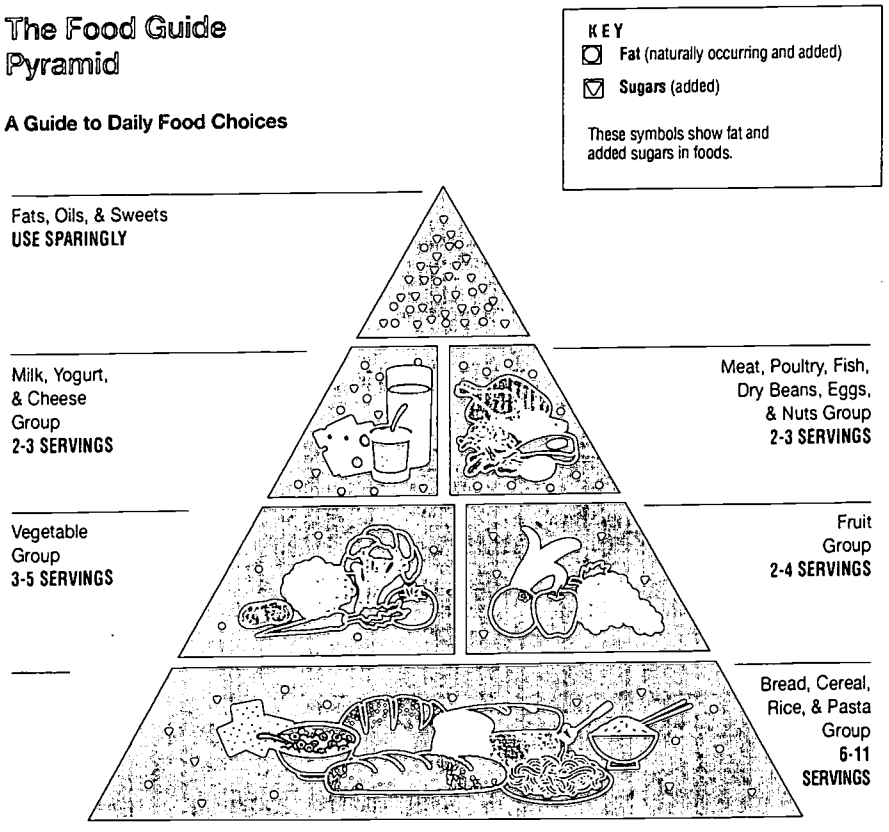
3. Accommodations available in the home allowing for preparation of foods;

4. Convenience.

The ability to obtain traditional foods may depend on the cultural ties that the family has established within the community. The availability of inexpensive ethnic eateries and the ability to communicate while shopping for foods are additional factors that influence food choices for families new to an area.

It is important for professionals working with families to be open-minded in their approach to nutrition education. Each child's needs should be looked at individually. When talking with families, sharing and exchanging stories about traditional foods used to celebrate special events often enhances communication. It is helpful for the professional to acquire information from the family about culturally healthy foods used for medicinal purposes. In addition, it is important to inquire about foods that are traditionally avoided. A good working rapport between the professional and family affords the opportunity to promote nutritional education and to introduce new foods.

While many are familiar with the traditional food pyramid for adults shown at right, there are also food pyramids available for different ethnic groups. These pyramids present typical regional practices and can be useful to help interventionists understand different cultural practices and assist families in integrating traditional foods into their daily diets. To obtain food pyramids for different cultures visit the U.S. Dept. of Agriculture website at: www.nal.usda.gov/fnic



Source: U.S. Dept. of Agriculture

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NUTRITION SCREENING

The purpose of nutrition screening is to identify children who may benefit from nutrition assessment and intervention. Nutrition screening and nutrition assessment differ in that a nutrition assessment is a more in-depth study of the child. While all early intervention staff should be able to administer a nutrition screening, a qualified nutrition specialist must carry out the assessment, since nutrition education and interpretation of growth charts and data are usually part of the assessment. Although staff and parent concerns are the primary methods for identifying children at nutritional risk, many children with nutritional concerns will not be identified unless standardized tools are used.

A nutrition screening tool is designed to survey a child in the following areas:

1. Diagnosis and medical conditions;
2. Drug & nutrient interactions;
3. Food allergies and intolerances;
4. Feeding concerns;
5. Variety of diet;
6. Growth.

Although there are several simple assessment tools (see Appendix Four) that can be used for this purpose, the Connecticut Birth to Three Nutrition Task Force developed the *Birth to Three Nutrition Screening*. See Appendix Five. This screening instrument is easy to administer and quickly identifies the need for nutrition services. It is recommended that a staff member complete the instrument with the parent and not leave it for the parent to complete alone.

Screening for feeding, growth, and nutrition concerns can easily be completed as part of the initial intake process with the parent or sometime during the first six months of enrollment in the Birth to Three System after the interventionist has developed a relationship with the parents. Because children's growth and development is continual, screening for nutrition concerns should be a constant, ongoing process. A child's food habits, food intake, and growth change rapidly during the earliest years and needs of both the child and caregiver change as well. Along with each periodic review of the IFSP, other times to consider reviewing nutrition issues would be:

- During infancy with the introduction of solids;
- During the transition from breast to bottle feeding;
- When a child is weaning off the bottle or from breastfeeding;
- During the transition from infant foods to table foods;
- With any surgeries or changes in the child's medical status;
- During the transition from tube feedings to oral feedings.

Red Flags

Children with medical conditions may have nutritional problems such as those listed in the following table. Since nutrition concerns may not be readily identified from the child's medical records, parent feedback from a nutritional screening tool as well as observation may be the best way to identify these concerns. A child with any of these conditions should be screened for feeding, growth, or nutrition problems. Early interventionists should ensure that parents or caregivers receive the education and support needed to achieve the child's nutrition outcome.

MEDICAL CONDITIONS	NUTRITION CONCERNS										
	Altered Nutrient and/or Calorie Needs	Problems with the Oral Cavity	Nutrient Deficiencies	G.I. Problems – (constipation, diarrhea, vomiting)	Poor Appetite/Intake	Delayed Feeding Skills	Malabsorption	Nutrient-Drug Interactions	Poor Growth/Weight Gain	Oral Sensitivity	Inappropriate Feeding Behavior
AIDS/HIV	○	○	○	○	○	○	○	○			
Autism/PDD			○		○	○				○	○
Bronchopulmonary Dysplasia (BPD)	○					○		○			
Cancer	○		○		○		○	○		○	
Cardiac Problems/ Congenital Heart Disease	○		○		○		○	○			
Cerebral Palsy	○	○	○	○	○	○		○	○		
Cleft Lip or Palate	○	○				○					
Cystic Fibrosis	○		○	○	○		○	○			○
Diabetes	○							○		○	
Down Syndrome	○	○		○		○					○
Dysphagia (difficulty swallowing)		○	○		○	○			○		○
Failure to Thrive	○		○	○	○	○	○		○		○
Fetal Alcohol Syndrome	○	○			○	○		○	○		
Food Allergy	○		○	○			○		○		
Gastrointestinal Disorders	○		○	○	○		○		○		○
Hyperinsulinism	○										
Lead Exposure	○										○
Inborn Errors of Metabolism	○		○	○	○				○		○
Myelomeningocele/ Spina Bifida	○			○				○			
Nutrition Support (Tube or IV Feeding)	○		○	○	○	○			○	○	○
Prader-Willi Syndrome						○			○		○
Premature Birth/ Very Low Birth Weight (VLBW)	○		○		○	○			○	○	○
Renal Disease	○		○	○	○	○		○	○		
Seizure Disorder	○							○		○	
William's Syndrome	○	○	○	○	○	○				○	○

(Adapted from: *Children With Special Health Care Needs – A Community Nutrition Pocket Guide, 1997)*

Common Nutrient-Drug Interactions

Increasing or decreasing medications can affect a child's appetite, food intake, and meal schedule. Some medications must be taken with food or fluid, while others must be taken on an empty stomach. In addition, some medications can interfere with the normal digestive process by causing diarrhea, constipation, or nausea. Other medications may deplete specific nutrients from the body by decreasing absorption, altering metabolism, and increasing excretion. Children may be at nutritional risk if they are:

- Receiving chemotherapy;
- Using a drug for extended periods (six months or longer);
- Taking several drugs at one time;
- Taking medications that have nutritional side effects (for example, diarrhea with antibiotics).

Parents should check with their child's pediatrician, pharmacist, or nutrition specialist regarding their child's individual medications and any possible nutrition implications.

Food Allergies and Intolerances

Foods most likely to cause food sensitivity are milk and dairy products, eggs, soy, legumes (such as split peas, lentils, or kidney beans), peanuts, tree nuts (such as walnuts), wheat, fish, and shellfish.

Symptoms can vary greatly in degree, time of onset, location, and the amount of food eaten. The same food can produce very different symptoms in different people. Most symptoms occur within two hours of eating the food, but they can be delayed up to 48 hours. However, anaphylactic (severe allergic) reactions are immediate and life threatening. Children can experience this type of reaction after eating a very small amount of the food in question.

Below are some of the problems that can occur if a child eats something to which he or she is allergic:

Gastrointestinal	**Skin**	**Systemic**	**Respiratory**
Swelling of lips, mouth, and throat Abdominal pain Distention (swelling) Nausea Vomiting Diarrhea Colitis	Hives Eczema Edema Redness Itching	Failure to Thrive Anaphylaxis	Runny Nose Wheezing Cough
Neurological/Behavioral Headache	**Other Clinical Symptoms that may be Observed** Colic Conjunctivitis Otitis Media Irritability Tension Fatigue Seizures		

Identifying symptoms of a food allergy or intolerance can be difficult in young children. The infant or small child may be unable to communicate pain or discomfort. Symptoms such as persistent nasal congestion, wheezing, coughing, chest congestion, vomiting, diarrhea, constipation, skin rashes, irritability, and sleeplessness may indicate a food allergy. Parents should consult with their child's primary health care provider who will do a more complete assessment of the child's diet and medical symptoms.

Hypersensitivity to foods can greatly affect the health status of a child. If undiagnosed, the overall nutritional status and development of the child may be affected. When a food allergy or intolerance is suspected, the physician may recommend an elimination diet as part of the diagnostic test. If a food group is eliminated from a child's diet, even for a brief period, the opportunity for malnutrition can occur because a host of vital nutrients is being eliminated from the diet. It is extremely important that alternative foods or supplements replace these nutrients. It is also important to remember that sensitivity to a particular food may also indicate sensitivity to related foods. For example, a child allergic to soybeans may also be allergic to other legumes.

With food allergies, it is extremely important for parents and other caregivers to read all food labels carefully. Many foods can have multiple names. For example, milk can be disguised on a food label as casein, whey, lactalbumin, lactoglobulin, or ghee.

NUTRITION ASSESSMENTS

If screening indicates the need for further information, a detailed nutrition assessment is recommended. The food diary and growth charts are some tools that the nutrition specialist uses in an assessment.

Food Diaries

A 24 Hour Food Recall

This is a description of the type and amount of foods and fluids a person consumes during a day. This gives a general idea of how the child ate in the period of one day. This tool does not provide an accurate, detailed picture of how a child usually eats.

Three-Day Food Diary With Nutrition Analysis

This is a record of foods and fluids a person consumes in a three-day period. This diary provides valuable information on eating habits, meal times, food likes and dislikes, serving sizes, and food texture preferences. Actual calorie and nutrient intakes can be determined from a well-recorded food diary. The following is one example of a food diary completed for a day, illustrating the important information to include in the food diary (date, meal, food eaten, and quantity of food eaten). Only food and fluids that are actually consumed should be written in the food diary.

Sample Food Diary

DATE: Sunday, 1/9/2000	
MEAL: *Breakfast*	6 oz. 1% milk ½ banana ½ cup Cheerios®
Snack	3 oz. orange juice ½ bagel with butter
Lunch	4 oz. cheese ravioli 4 oz. jar garden veggies 4 oz. fruit yogurt 4 oz. 1% milk
Snack	½ oz. box raisins
Dinner	5 ½ oz. pasta with tomato sauce 4 oz. fruit yogurt 4 oz. 1% milk
Bedtime	6 oz. 1% milk

Growth Charts

When using growth charts that include measurements for weight, length and head circumference, it is important that the measurements and age determination are accurate. Many of the children in the Birth to Three System fall below the fifth percentile for growth. Growth charts are useful tools to screen, evaluate and monitor growth. The National Center for Health Statistics (NCHS) growth charts are the ones used in the United States. NCHS charts do not represent the growth of the child with special needs, but are typically used as a starting point for monitoring growth. There are NCHS charts for boys as well as girls, with charts for ages 0 to 36 months and 2 to 18 years of age for each. There are a number of growth charts for children with certain health conditions such as Down Syndrome and infants born prematurely. This year, new growth charts will be introduced that are based on Body Mass Index (BMI).

<u>What is normal growth?</u>

When looking at a growth chart, there is an area to document a child's length, another for weight, another for head circumference, and another area to compare the child's weight and length. In each of these chart areas there are white areas with curved lines. These curved lines represent percentiles for each parameter being measured. The darkest curve represents the 50th percentile and is where a majority of children will fall on the chart. Normal growth is generally represented by length and weight measurements that fall within the 10th and 75th percentiles when plotted on a growth chart. *Measurements that fall below the 10th and above the 75th percentiles may identify nutrition risk factors and indicate that a nutrition evaluation is needed.*

The most useful information is to plot a series of measurements for each parameter in order to see a child's own growth pattern. Measurements that form an upward curve indicate growth. The weight/length chart is used to determine adequate weight for a child small in stature. Growth charts are periodically updated. The most current growth charts can be accessed via the Internet at www.cdc.gov/nchs/nhanes.htm (See Public Health interest items – Growth Chart.

RECOMMENDED DIETARY INTAKE

Generally, the variety in a child's diet will increase and portions will be adjusted as the child's appetite changes. Table 1 below, created by the University of Connecticut Cooperative Extension System, helps to illustrate the general recommendations for infants birth to 12 months. For each age group the child should be eating the foods that are listed. The amounts may change from day to day and smaller amounts are listed for younger children.

Table 2, adopted from the Cornell Cooperative Extension System gives the corresponding information for children ages one year to three years. In order for children to obtain adequate nutrition, these quantities of food must be consumed every day, but remember that portion sizes for children are smaller than those for adults. It is also highly recommended that parents consult their child's physician regarding adherence to these recommendations for their child. A pediatric nutrition specialist would tailor a child's diet to meet that child's individual needs.

Table 1: Recommended Daily Intake for Children Birth to 12 Months

Foods	Birth to 3 months	4 months to 5 months	6 months to 8 months	9 months to 10 months	11months to 12 months
Breast Milk	Every 2-3 hours	Every 2-4 hours	Every 3-4 hours	Every 4-5 hours	Every 4-5 hours
Iron Fortified Infant Formula	18-40 oz.	24-45 oz.	24-37 oz.	24-31 oz.	24-31 oz.
Infant Cereal		1-4 Tbs.	6-8 Tbs.	6-12 Tbs.	6-12 Tbs.
Fruit Juices		1-2 oz.	1-4 oz.	3-4 oz.	3-4 oz.
Vegetables			1-4 Tbs.	3-6 Tbs.	3-6 Tbs.
Fruits			1-4 Tbs.	3-6 Tbs.	3-6 Tbs.
Finger Foods				Small servings of soft fruit, cooked vegetables, macaroni, breads, and certain cereals.	
Meat, Beans, Peas, Lentils				2-4 Tbs.	4-6 Tbs.
Yogurt, Cheese, Cottage Cheese				Small servings	Small servings
Egg Yolk (cooked)				3 per week at most	3 per week at most

Table 2: Recommended Daily Intake for Children Ages One to Three Years

Foods	One year old	Two years old	Three years old
Breads, Cereals, Rice, Pasta *Six servings per day*	¼ to ½ slice bread or 1Tbs. cooked cereal	½ slice bread or 2 Tbs. cooked cereal, rice or pasta or ½ to 1/3 cup ready to eat cereal	½ to ¾ slice bread or 2 to 3 small crackers or 3 Tbs. cooked cereal, rice or pasta or 1/3 cup ready to eat cereal
Fruits *Two servings per day*	¼ fresh fruit or ½ cup juice or 1 Tbs. cooked fruit	¼ to ½ fresh fruit or ½ cup juice or 2 Tbs. cooked fruit	½ fresh fruit or ½ cup juice or 3 Tbs. cooked fruit or 3 Tbs. dried fruit
Vegetables *Three servings per day*	1 Tbs. cooked vegetables or 1/3 cup juice	2 Tbs. cooked vegetables or ½ cup juice	3 Tbs. cooked vegetables or ½ cup juice or 3 small pieces raw vegetables
Meat, Poultry, Fish, Eggs, Dry Beans *Two servings per day*	1 Tbs. meat, poultry, fish or 1 egg 3 to 4 times weekly	2 to 3 Tbs. meat, poultry, fish or 1 egg 3 to 4 times weekly	½ oz. meat, poultry, fish or ¼ cup cooked dry beans or 1 egg 3 to 4 times weekly or 1 Tbs. peanut butter
Milk, Yogurt, Cheese *Three servings per day*	¾ cup whole milk or ¼ to ½ ounce cheese	½ to ¾ cup whole or low fat milk or yogurt or ¼ to ¾ oz. cheese	½ to ¾ cup low fat or skim milk or yogurt or ½ to 1 oz. cheese
Fats, Oils, Sugars	use sparingly	use sparingly	use sparingly

Notes on Milk

For one-year olds: The serving size of milk is ¾ cup whole milk, which is more than the lowest recommended serving size for a two-year old (½ - ¾ cup). A one-year old needs whole milk and a greater quantity of milk to get the nutrients and food energy required at that age.

For two-year olds: The type of milk recommended for two-year olds may be whole or low fat. The Dietary Guidelines recommend low fat or skim milk for healthy Americans ages two years and over. The type of milk offered should be based on the individual needs of the child.

Pediatric Formulas

There are numerous formulas available for feeding the infant and small child. The child's physician and nutrition specialist should be helpful in determining the formula best suited for a child. Formulas should never be discontinued or changed without first consulting the physician. Home-prepared formulas are not recommended primarily for the greater risk in contaminating the formula with germs that can be harmful to the child. See Appendix Six for more information on infant formulas.

Foods to Avoid with Young Children

Before age 1 due to allergic reaction -	cow's milk, egg whites, seafood, chocolate, honey, tomatoes, and citrus fruits
Before age 3 due to choking risk -	raisins, grapes, nuts, peanut butter, pieces of hot dog, raw carrots, and popcorn

FEEDING

Feeding skills should develop in an orderly, predictable series of oral-motor skills. As each new skill is acquired, foods that match that skill should be introduced to the child as illustrated in Table 3 below. Some children with feeding issues may skip stages or follow a slower or different progression sequence.

Table 3: Progression of Feeding Skills and Food Choices for a Typically Developing Child

AGE	CHILD SKILLS	FOOD CHOICES
1 - 2 months	○ Suckle ○ Tongue movement front to back ○ Rarely drools	○ Breast or bottle feeding
2 - 4 months	○ Head control ○ Minimal liquid loss when sucking ○ Mouth opens in expectation of nipple	○ Breast or bottle feeding
4 - 6 months	○ Voluntary sucking begins ○ Munching emerges ○ Lips purse and smack ○ Tongue projects intentionally ○ Mouths objects ○ Recognizes bottle	○ Begin strained foods
6 - 8 months	○ Can sit alone ○ Lips close around a spoon ○ Chewing begins ○ Tongue lateralization begins ○ Brings food to mouth ○ Begins holding bottle ○ Begins sipping from a cup	○ Advancement of solid foods ○ Begin large, soft finger foods ○ Begin juice from a cup
8 - 10 months	○ Uses upper lip to remove foods from spoon ○ Drools only when teething ○ Begins to finger feed ○ Holds own bottle ○ Sips from an open cup	○ Begin finely chopped or mashed table foods
10 - 12 months	○ Lips close when swallowing ○ Rotary chewing ○ Begins holding cup ○ Bites through solids ○ Begins self spoon feeding	○ Begin chopped table foods ○ Begin small finger foods

Identification and Intervention for Feeding Problem

Children are identified as having feeding problems when they are either unable to eat or refuse to eat certain foods due to physical or behavioral reasons. Feeding problems can result in slow growth, poor weight gain, nutrient deficiencies, dehydration, constipation, psychosocial problems, refusal to consume types of foods, appetite distortions, and dental cavities.

Since children with special needs demonstrate a greater number of feeding and eating disorders than do typical children, it is important to identify and address such issues early. Some clues for identifying possible feeding problems in young children include:

1. The child is hypersensitive to touch in and around the mouth;
2. The infant has difficulty sucking from the bottle or breast;
3. The infant takes an excessive amount of time to swallow a small amount of liquid;
4. The infant or child loses excessive liquids or foods from mouth during feedings;
5. The child has difficulty tolerating varying food consistencies and textures according to age-expected levels;
6. The child coughs, chokes, gags, spits up, or vomits excessively;
7. The child uses limited movements of jaw, tongue, lips, and cheeks when chewing foods or drinking from a cup;
8. There is poor lip closure around a nipple, spoon, or cup;
9. The child experiences severe dental caries (cavities).

The best way to assess whether a child has feeding problems is to observe him during a feeding time in a familiar environment with the parent or caregiver. When feeding problems are identified, they can usually be attributed to oral motor, positioning, or behavioral issues. Because these issues may exist alone or in combination, it is important for the appropriate early intervention team members to work closely with the family when assessing and addressing feeding problems. Table 4 gives examples of some of the many roles team members may play in this effort. Some of these roles may overlap and each team member should feel comfortable in reinforcing the other team members' recommendations, reducing the need for additional professionals to interact directly with the child.

Table 4: Roles of the Early Intervention Team Members in Addressing Feeding Problems

Team Member	Role
Speech Pathologist	▫ Improves oral-motor skills for safe management and swallowing of liquids and solids ▫ Reduces oral hypersensitivity to touch, taste, textures, and temperatures; ▫ Safely introduces oral liquids and foods while allowing the child to maintain a sense of control; ▫ Offers strategies to the family for slowly and safely introducing new tastes, textures, and consistencies;
Occupational Therapist	▫ Works closely with the speech therapist on developing a "sensory diet" for the oral-motor area when an aversion to foods is noted due to either a hyper or hypo sensitivity to textures or touch; ▫ May also help the family with arranging the setting to promote a positive eating experience.
Physical Therapist	▫ Educates the family and other caregivers on specific handling techniques or body positions that help develop the appropriate head, neck, and trunk control essential for eating and swallowing; ▫ Suggests to the family, adaptations to the child's seating to promote optimal positioning of the child which sometimes requires the ordering of appropriate positioning equipment when adaptations cannot be made to the child's chair.
Nutrition Specialist	▫ In conjunction with the physician, ensures that the intervention plan offers adequate calories and nutrients for the child in order to decrease the severity of these feeding problems.
Early Childhood Special Educator	▫ Works in concert with the team members and family in developing eating skills.

Depending on the child's and family's needs, other team members such as a social worker or behavioral specialist may be needed to support the family.

Swallowing Dysfunctions

A "safe" swallow is essential for eating to take place. A swallowing dysfunction can affect a child's food intake, nutritional status, and their overall health.

The following signs may indicate when referral to the primary health care provider for further evaluation of a possible swallowing dysfunction is recommended:

1. History of repeated upper respiratory infections and pneumonia;
2. History of frequent spitting up, coughing/choking/difficulties breathing during and after meals;
3. Wet/noisy upper airway sounds;
4. More than one swallow needed to clear a bolus (food ready to be swallowed);
5. Drooling/pooling of saliva;
6. Nasopharyngeal regurgitation (loss of food or liquid through nose);
7. Food refusal behaviors (for example, turning head away, pursing lips together, pushing food away, spitting out foods/fluids);
8. Overreaction to foods/fluids around the mouth (e.g., gagging, crying, strong refusal behaviors);
9. No reaction to food/fluid (for example, no awareness of food on lips, no mouth movement, no attempt to swallow).

Depending on the child, a swallowing problem may be easily determined through observation or it may require more involved medical procedures using X-ray or fiber optic equipment. Similarly, the intervention for eliminating a swallowing problem will also vary from minor changes in positioning to changes in diet and/or interventions, which require medical oversight. It will be up to the Birth to Three team, including the family and physician to determine whether any of these procedures are early intervention services or medical treatments.

Gastroesophageal Reflux (GER)

A common issue for young children related to feeding is Gastroesophageal Reflux, or GER. GER is a condition where the contents of the stomach frequently re-enter the esophagus (throat). It happens when the sphincter between the stomach and the esophagus does not work properly. The sphincter acts as a door between the stomach and esophagus. GER may be observed as spitting up or vomiting. However, the symptoms of reflux may also be "silent". If any of the following signs or symptoms are

common in a child, referral to the primary health care provider for further evaluation is recommended:

1. vomiting
2. weight loss
3. oral thrush
4. chronic constipation
5. eats small amounts frequently
6. noticeably wet pillow after sleeping
7. wet burps
8. heartburn
9. foul or sour breath
10. arching back during feeding
11. frequent respiratory illness

Tube Feeding

Tube feeding is used when children cannot safely take in enough calories by mouth for proper growth and development. Below are the signs and symptoms which, if observed, may indicate the need for tube feeding. Check for the following:

1. Child is unable to eat at least 80% of estimated calorie needs or 90% of their fluid needs by mouth;
2. History of GER with failed treatment;
3. Repeated upper respiratory infections or pneumonia;
4. "Wet cough" noted during and/or after feedings;
5. History of weight loss, or no changes in weight or height over a period of time;
6. Vomiting, choking, coughing, changes in skin color, or other signs of distress during feedings;
7. Feeding times exceed a total of 4 hours each day;
8. Craniofacial anomalies;
9. Tracheostomy tube.

There are several types of feeding routes used to provide the necessary calories, including nasogastric, gastrostomy, and jejunostomy tubes:

Nasogastric tubes (NG tubes)

This soft tube runs through the nose and down into the stomach. Surgery is not required to place this tube and parents can be taught how to do this while at home. When the tube is in place, the child can still eat by mouth. NG tubes are used when nutrition supplementation is needed on a short-term basis. The child may experience discomfort in the mouth or throat and there may temporarily be an aversion to oral stimulation.

Gastrostomy tubes (G-tube)

This tube is placed into the stomach wall and provides food directly to the stomach, bypassing the mouth altogether. Surgery is required in order to place the G-tube, and the tube is hidden under clothing. This type of tube can be used on a long-term basis. Sometimes the child with a G-tube can continue to eat by mouth as recommended.

Jejunostomy tubes (J-tube)

This tube is placed directly into the wall of the jejunum (the second portion of the small intestine) and provides food directly into the small intestine by bypassing the mouth and stomach altogether. Surgery is required in order to place the J-tube, and the tube is hidden under clothing. This type of tube can be used on a long-term basis. Rarely can the child with the J-tube continue to eat by mouth.

Common Tube-Feeding Complications

Complications that occur with G-tube or J-tube fed children can be categorized as gastrointestinal, mechanical, metabolic, and psychological.

- Psychological complications involve the refusal of the child to eat foods orally.
- Gastrointestinal complications can include vomiting, diarrhea, and constipation.
- Metabolic complications can result in dehydration, overhydration, electrolyte imbalances, and failure to achieve appropriate weight gain.
- Mechanical complications can result in obstruction (blocking) of the feeding tube or aspiration of formula into the lungs.

Monitoring a Child While on Tube Feedings

Table 5 lists examples of the questions that caregivers for children on tube feedings will be asked by the nutrition specialist, visiting nurse, or physician. This should occur on a regular basis in order to ensure that the child is receiving adequate nutrition to promote growth and good health while on tube feedings.

Table 5: Important questions for families whose children are tube fed

1.	What product is going into the tube?
2.	How many ccs or fluid ounces per feeding?
3.	What times are the feedings?
4.	Are night feedings ever turned off?
5.	Are feedings by pump, bolus, or continuous drip?
6.	How much water is used to flush the tube?
7.	How much water is added to the formula?
8.	Does the child appear comfortable during and after feedings?
9.	Does the child show signs of hunger?
10.	Does the child have constipation or diarrhea?
11.	Does the child vomit frequently?
12.	Is the child gaining adequate weight?
13.	Do you have any problems getting the formula?
14.	Are there any problems with the G-tube site?
15.	Does the child remain upright during feedings?

Transition to Oral Feeding

Returning to oral feedings may be a realistic goal for some children, but transition time will vary greatly from child to child. During this transition, the control of feeding returns to the child. Hopefully, the nutritional status of the child will remain stable as the changes occur. It is vital that the nutrition specialist be involved with the child's care during this transition in order to:

- Help the family identify signs of hunger;
- Adjust feedings, in connection with physician, to allow for hunger to occur;
- Recommend appropriate foods;
- Monitor height, weight, and head circumference;
- Monitor food and fluid intake via food diaries;
- Provide family support to continue oral feedings despite the child's possible food refusal or behavior problems.

LACTATION FOR THE INFANT WITH SPECIAL NEEDS

Mothers who choose to breastfeed their newborn may find this difficult if their child is born with special needs. Often they will look to their early interventionist for information. This section offers some basic information on lactation to assist interventionists in the Birth to Three System. Mothers of infants with special needs can use general breastfeeding information that is helpful to all mothers of nursing infants, but they may also need additional support and education to effectively deal with the unique needs of their own infant. In that case, they should be referred to their pediatrician or a lactation specialist.

Breastfeeding offers the same nutritional benefits to the infant with special needs as it does for any newborn, but it has several additional advantages:

1. Reduces risk for development of allergies;
2. Imparts greater immunity from infections;
3. Is more digestible than standard formula;
4. Makes stools soft and easy to pass, which can help with bowel problems;
5. Improves mouth and tongue coordination through sucking;
6. Provides additional stimulation of skin-to-skin contact to infants with low muscle tone;
7. Increases eye-hand coordination;
8. May assist with later speech development by exercising the muscles around and in the mouth.
9. Enhances the relationship between mother and baby.

Grief or guilt may be the first feelings a mother experiences if she has given birth to an infant with a physical or developmental impairment, particularly if delivery brings first knowledge of the condition. Initially, this can overwhelm a mother's (and father's) ability to obtain and absorb information about caring for their infant. If the family had planned to breastfeed their infant, they may wonder if it is still possible in light of their infant's condition. The role of the early interventionist is to offer emotional support, appropriate education, and referral so that the mother may attempt nursing if that is what she chooses. If a mother chooses not to nurse or is unable to nurse due to the infant's condition, she should be equally supported in that decision. When information is provided, it may need to be repeated more than once, given that parents are dealing with many emotions regarding their baby's health as well as their own fatigue.

Breastfeeding Should Not Be Recommended If

The mother:
- has HIV/AIDS
- is abusing alcohol or drugs
- has a medical condition requiring certain unsafe medication which passes through breast milk
- has active tuberculosis (prior to treatment)
- has herpes lesions on her breast

Or the infant:
- has galactosemia

Breastfeeding an infant with special needs may work most effectively in one of three ways:

1. Nursing directly from the breast for all feedings if the infant is able;
2. Pumping breast milk for all feedings if the infant cannot nurse directly; or
3. A combination of nursing and pumping milk or calorie enhanced formula.

Each infant should be assessed to determine the appropriate feeding method. Direct nursing or pumping may require additional time and perseverance from the mother of an infant with special needs; however, knowing that she is providing an optimal source of nutrition may empower her. It is important to remember that a woman's milk supply is established during the first six weeks after delivery. A regular schedule for nursing or pumping needs to be established to assist and enhance adequate breast milk production.

Nursing Directly From the Breast

Infants with conditions such as Down Syndrome, Phenylketonuria (PKU), cleft lip and palate, cardiac defects, low birth weight, or neurological impairments may be nursed successfully if parents have access to specific information tailored to their infant's needs (for example, positioning and timing of feedings, adaptive feeders). It is important that parents work with practitioners who are knowledgeable in breastfeeding techniques for their infant's specific condition. This may be a lactation consultant, nutrition specialist, neonatologist, speech pathologist, or developmental pediatrician who has specific training in this area or a combination of these practitioners.

Signs Of Adequate Intake In Breastfed Infants

- 8-12 feedings in 24 hours;
- audible swallowing in baby when mother's milk "lets down";
- baby alert with healthy skin;
- baby is content between feedings when mother's milk comes in (without other indicators of fussiness);
- by the fifth day, 6 or more wet diapers per 24 hours;
- 3-8 soiled diapers per 24 hours for the first six weeks;
- baby gains 5-7 ounces per week (or 1 ounce per day);
- baby recovers birth weight by two weeks of age (newborns normally lose some weight in the first week of life);
- feedings last at least 10 minutes per breast and generally not more than 20 minutes per breast;

Pumping Breast Milk

For infants who are unable to nurse directly from the breast due to a weak suck, those who are unable to latch onto the breast, or those who become overtired with feedings, pumping is the effective way to offer the benefits of breast milk. Pumping can often be helpful if the mother cannot decide whether she wants to breastfeed or not. It can offer her time to make the decision that is right for her, without losing the opportunity for establishing milk supply for her infant. Electric pumps can be rented from hospital maternity units, home care companies, and medical pharmacies and are most effective in establishing and keeping a mother's milk supply (vs. hand-powered pumps or manual expression). The ideal pumps are those with ability to pump both breasts at the same time. The volume of milk collected will depend on the mother's ability to relax and have "let down" (milk release) with a pump vs. nursing. Frequent short pumping sessions (10 minutes) increase prolactin levels and milk production more than longer (20 minutes) and less frequent sessions. Pumped milk can be enhanced in calories with additives if weight gain is an issue. Some insurance companies may cover the cost of pump rental due to medical needs of the infant.

Tips On Initiating Milk Supply Without Infant Suckling

- Begin pumping as soon after delivery as condition permits;
- Initiate use of electric pump while in hospital;
- Pump at least 7 times in 24 hours and/or a total of at least 100 minutes per day;
- Allow a rest period for uninterrupted sleep of at least 6 hours;
- Use a "double" pumping system (pumping both breasts simultaneously) to decrease total pumping time;
- Prepare the breast with warm soaks, hot showers, gentle stroking, and light massage to maximize the production of milk.

Nursing and Pumping or Supplemental Formula

Sometimes an infant may be able to nurse from the breast, but tires from a full day of feedings. In this case, a lactation consultant, physician, or nutrition specialist may recommend some nursing to promote mother and infant bonding, but supplement it with additional pumped breast milk or formula from a bottle with a soft nipple. If weight gain is an issue, either the pumped breast milk or formula can be enhanced in calories beyond 20 calories per ounce by concentrating the formula further, and/or adding additional carbohydrate or fat. A qualified pediatric nutrition specialist should be able to provide recipes that enhance the calories in breast milk or formula. Haberman Feeders and Supplemental Nursing systems, available from the Medela Company, can also assist infants who have difficulty nursing from the breast or who need additional calories while nursing from the breast. See Appendix Four.

Storage Information For Breast Milk

Room Temperature (less than 78°F)	*In Refrigerator*	*In Freezer*
Freshly expressed breast milk *(6-8 hours)*	72 hours	3 months in refrigerator freezer 6-12 months in deep freezer
Previously frozen breast milk *(1 hour)*	24 hours	Do not refreeze

(From: *A Review of the Medical Benefits and Contraindications to Breastfeeding in the United States)*

Thawing Frozen Breast Milk

DO	*DO NOT*
Thaw frozen breast milk gradually, in its container, under increasingly warm water	Defrost breast milk by using boiling or very hot water
Or, set it in another container full of warm water and slowly add warmer water until the milk is thawed	Defrost breast milk in a microwave oven, because uneven heating may cause "hot spots" that could burn the baby
Gently swirl the container to mix the milk before feeding it to the baby because the milk usually separates while standing	Microwave, because it may alter proteins and destroy some protective components of the milk

Dietary Needs of Nursing Mothers

Breastfeeding increases the mother's requirements for most nutrients since she produces an average of 3.25 to 3.5 cups of breast milk daily during the first four or five months of the baby's life. The Recommended Daily Allowances (RDAs) are higher during lactation than at any other stage of a woman's life. Infants of women who do not get adequate nutrition will still get the milk and nutrients they need, but the mother's

body will suffer from the lack of nutrients. Mothers need to select a variety of foods that meet their increased energy, protein, and other nutrient needs and avoid the temptation to restrict intake in order to lose weight.

Some general guidelines are that nursing mothers should:

1. Drink plenty of fluids. Fluids do not stimulate milk production or letdown, however they do replace fluid lost while nursing. Women should drink to satisfy thirst, preferably with milk, juice, or water. Coffee, tea, and soda that contain caffeine are okay in moderation, however they are diuretics. Occasional, limited use of alcoholic beverages is acceptable;
2. Eat a variety of foods;
3. Eat regular meals and nutritious snacks since nursing mothers tend to get hungrier during the day;
4. Eat a little more than usual. Women who breastfeed tend to have a natural increase in appetite. Calorie needs are about 500 more per day than it took to maintain weight prior to pregnancy;
5. Eat foods that are high in sugar or fat in moderation as long as nutritious foods make up most of the mother's diet;
6. Avoid dieting to lose weight rapidly.

Stress, anxiety, and fatigue can all inhibit let down of milk while an infant is nursing. The mother of an infant with special needs may be feeling these emotions during the first month of a baby's life. Nutrition and rest play a very important role in helping a mother cope with the additional demands breastfeeding places on her body. Well-nourished, well-rested mothers will have better breastfeeding success for their infant with special needs. See Appendix Four for more information on breastfeeding.

NUTRITION CARE FOR PREMATURE AND LOW BIRTH-WEIGHT INFANTS

Medical advances in the respiratory management and nutrition support of premature and low birth-weight infants over the past 10-15 years has led to dramatic increases in the survival rate of these babies. This is particularly true for the infant who is born weighing less than 1000 grams (less than 2.2 lbs.) which is called Extremely Low Birth Weight (ELBW). Although, prematurity is broadly defined as infants born less than 38 weeks gestational age, there is considerable diversity among infants classified as "pre-term". Many prenatal and postnatal factors contribute to this, such as the infant's intrauterine environment, medical history and current medical status, growth, nutritional history and current nutritional status, genetics, and family issues.

Many pre-term infants are discharged from the hospital when they weigh approximately 1800-2500 grams (4-5 lbs.) and are 35-40 weeks gestational age. An infant is usually ready to go home when acute medical problems have been resolved. However, some infants will be discharged with chronic but stable conditions requiring ongoing medical management. This would include infants with bronchopulmonary dysplasia (BPD), short

bowel syndrome, or other medical conditions related to prematurity. These infants will require additional medical and developmental follow-up in the community. *Extremely Low Birth Weight infants (less than 1000 grams at birth) are automatically eligible for the Birth to Three System for up to 6 months corrected age.*

Initial birth weight is important because it can be a predictor of an infant's growth potential and overall health status in infancy and childhood.

Birth Weight Category Terms Used Frequently For Premature Infants:

LBW – low birth weight < 2500 grams.
VLBW – very low birth weight < 1500 grams.
ELBW – extremely low birth weight <1000 grams.
(LBW, VLBW, and ELBW terms do not indicate a particular gestational age)
SGA – small for gestational age; birth weight is < 10th percentile for gestational age on either National Child Health Statistics or Lubchenco growth chart.
AGA – appropriate for gestational age; birth weight is between the 10th-90th percentile for age on National Child Health Statistics or Lubchenco growth chart.

Nutritional Needs

Premature and low birth weight babies need special attention because they have very different nutritional requirements than a full term newborn. They have higher requirements for nutrients such as protein, calories, calcium, phosphorous, iron, vitamin A, and zinc to support catch up growth. Special products designed to meet these nutrient needs are used during hospitalization. These include products for fortifying breast milk (i.e. human milk fortifier) and special premature formulas such as Similac®, Special Care 24®, Enfamil Premature 24®, and "Preemie" SMA 24®. These products are generally higher in calories (24 calories/oz. vs. 20 calories/oz.), protein, vitamins, and minerals than standard infant formulas. Some premature infants may need to continue to need human milk fortifier or premature infant formulas after discharge from the hospital, due to bone disease of prematurity.

In the past, once premature infants were discharged, it was common practice to concentrate standard cow's milk-based formulas to 24 calories/oz. or higher. Now, two formulas are available as transitional feedings designed for premature infants weighing 1800 grams or more (Neocare® and Enfamil 22®). These products are to be given for a full year to promote catch up growth and are preferable to standard infant formulas. The introduction of solids should begin after the corrected age of four months or later with the recommendation of the infant's pediatrician.

Many women wish to breastfeed their premature or low birth weight baby and this should be strongly encouraged. Many of these infants will leave the hospital fully breastfed, while others will be making the transition from bottle to breast. The breastfed premature infant requires both multivitamin and iron supplementation. They will also need assistance with positioning during feeding and growth monitoring.

Growth Monitoring

The National Child Health Statistics (NCHS) growth charts may be used to evaluate the growth of a premature infant provided the measurements are corrected for gestational age. Weight should be corrected until the child is 24 months of age, length until 36 months of age, and head circumference until 18 months of age. Because premature and low birth weight infants are at greater risk for poor growth, they should be measured regularly by their pediatrician or other health care provider. Parents may also be anxious about weight gain and may need reassurance and support in carrying out feeding plans for their infant to promote optimal growth.

Feeding Issues

Healthy, but premature and low birth weight infants show a range of feeding problems that are less likely to be seen in full-term infants, for example:

- Premature infants of 34-36 weeks gestational age may not have developed their ability to suck or swallow as yet;
- Neonatal Intensive Care Units (NICUs) often require infants to be fed by several people and allow parents only limited feeding opportunities;
- Parents may be stressed regarding their infant's medical progress and growth status;
- Infants may have negative oral experiences, such as feeding tube placement, and have limited mouth play with nipples;
- Some babies may be overly sensitive to objects in their mouth due to previous negative experiences. This may include different nipples or transitions in food textures from strained to lumpy;
- After discharge, some infants may experience setbacks in feeding and growth;
- For some babies, nipple feeding may increase energy expenditure.

Below are some recommendations and tips to promote feeding success for premature or low birth weight infants.

- Small, frequent feedings;
- Nutritionally appropriate premature transition formula or supplemented breast milk;
- Calm feeding environment (quiet room, low light);
- Prefeeding preparation (swaddling);
- Positioning to improve suck (chin tucked slightly, head supported, one or both arms forward, straight trunk, bent hips);
- Special feeding equipment (soft nipple, angled neck bottle);

- Cheek and lip stabilization (gently draw cheeks forward);
- Jaw support.

In summary, premature and low birth weight infants have increased nutritional needs and are at risk for poor growth and feeding difficulties. Feeding milestones should be based on appropriate developmental readiness rather than developmental age. Regular growth monitoring, nutritional assessment, support, and intervention when necessary will smooth the transition home from the hospital and establish an appropriate feeding pattern for these infants.

ALTERNATIVE AND COMPLEMENTARY MEDICINE

Alternative and complementary medicine encompasses a wide variety of practices and treatments. For the purpose of this document, discussion is limited to herbal preparations, vitamins, and supplements. Many families seek alternative or complementary nutritional therapies either as a single therapy or as an adjunct to more traditional physician based care. Some complementary therapies are common in certain cultural groups. It is important to be aware of these cultural values and show respect for these practices.

Daily, we hear nutrition-related stories from the media, friends, family, and professionals. There is a lot of consumer misinformation available especially via the Internet. Professionals must keep an open mind and respond to these therapies based on sound scientific information. Many sources are not validated and many treatments have not been shown to be effective. Although there have been scientific studies completed for adults, clinical studies are still needed in the United States to test the safety and efficacy of herbal preparations, vitamins, and supplements for use with infants and children.

The public is often unaware of the potential dangers of medication interactions and people often feel that plants and vitamin supplements cannot hurt you. Consumers may also be uneducated in how much to take and when. Any substance taken internally has the potential to do damage. *The child's physician should be made aware of any use of herbal or vitamin supplement preparations. If a breastfeeding mother is taking an herbal or vitamin supplement, this is also important information for the pediatrician.*

<u>Facts</u>

- Herbal products are not regulated by the U.S. Food and Drug Administration the way medications are.
- No safe and effective dosages of most herbal supplements have been determined for infants and children.
- Natural does not always mean safe.

TRANSITION FROM BIRTH TO THREE SERVICES

Part C of the Individuals with Disabilities Education Act (IDEA) requires that the families of all children leaving the Birth to Three System participate in a transition planning meeting and, with their service coordinator, write a Transition Plan. For many families, this will occur in preparation for their child's third birthday, and will involve the child moving on to preschool special education services or other types of community programs. However, this situation may occur sooner than age three if the child attains age appropriate skill levels or leaves the Birth to Three System by family choice. Whatever the case, for a child who has had nutritional concerns addressed by the Birth to Three System, identifying sources for ongoing nutritional support within their community will be important if the transition plan is to be comprehensive and effective.

Transition to Preschool Special Education

Birth to Three providers and families need to be aware of the subtle differences in focus and terminology that exist between the Birth to Three System and preschool special education services. While the family received services under Part C (Birth to Three) of IDEA, the focus of services and supports were on all of the child's developmental areas as well as the family's needs. Part B of IDEA, which governs the provision of special education for children ages three to twenty one, or until they graduate from school, focuses more narrowly on the educational needs of the child. For a child who is eligible for special education, school personnel will concentrate specifically on the child's learning needs and will identify specific goals, strategies, and services that will enhance educational progress. Consequently, the school will not continue to address the child's nutritional and feeding needs in the same way that the child's Birth to Three program had.

Transition to Community Services and Supports

A transition meeting and plan are required for all children who leave the Birth to Three System, even if they do not go on to preschool special education services. The child's service coordinator must arrange for the meeting to occur in a timely manner (at least 90 days before the child's third birthday) so that a family can experience a sense of closure and confidence with the ending of Birth to Three supports. If the Birth to Three program has been working with the family to address nutritional concerns, the continuation of these supports outside of the Birth to Three System will need to be addressed in the plan.

Medical and community resources for nutrition outside of the Birth to Three System include commercial health insurance, The Women Infants And Children (W.I.C.) Program and the Children with Special Health Care Needs Program. Whether these options work for each child will depend on the nature of the supports needed and the family and/or child's eligibility for these resources. See Appendix Four for more information on these two programs.

Child Nutrition Programs for Schools and Community Programs

When planning for the dietary needs of children while they are away from home, parents should work closely with all school, childcare, medical and other community personnel who are responsible for the health and well being of children.

There are some resources for children who have special dietary needs and who attend a program outside the home. Meals served to children in programs outside the home are often supported by funds from the U.S. Department of Agriculture. These funds are distributed through the Connecticut State Department of Education to:

- Schools on the National School Lunch and Breakfast programs and;
- Day Care Centers, Head Start Programs, and Family Child Care Providers on the Child & Adult Care Food Program.

Because of this federal support, it is possible for these programs to offer meals for free or at a reduced cost to enrolled children. These meals and snacks must meet certain nutritional standards and must be served to all children without regard to race, color, religion, national origin, sex, age, or disability.

Schools and daycare facilities are required to provide substitutions to the standard meal to children with disabilities when the disability restricts their diet. These substitutions must be provided at no extra cost to the parents. Although not required, sponsors may make substitutions or other menu changes to accommodate dietary needs of children without disabilities.

APPENDICES - INDEX

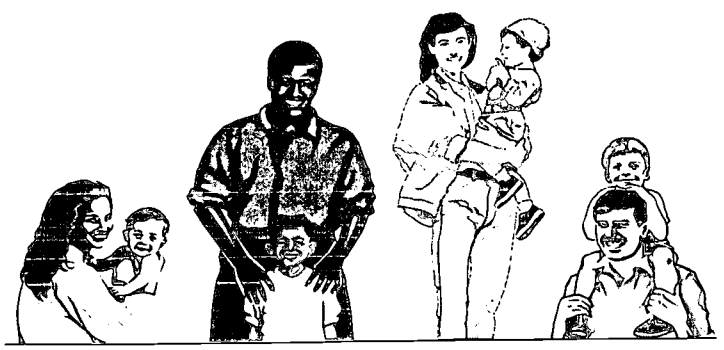
Appendix One

Mission

Connecticut Birth to Three System

The mission of the Connecticut Birth to Three system is to strengthen the capacity of Connecticut's families to meet the developmental and health-related needs of their infants and toddlers who have delays or disabilities. The system will ensure that all families have equal access to a coordinated program of comprehensive services and supports that:

- *foster collaborative partnerships*
- *are family centered*
- *occur in natural settings*
- *recognize current best practices in early intervention*
- *are built upon mutual respect and choice*



- collaboration - partnerships - family centered - opportunity - equal access - inclusion - choice - natural environments - best practice - comprehensive programs - mutual respect - teamwork -

Partnerships: *Supporting families requires a collaborative approach which encourages partnerships between the family, their community, service and health-care providers, schools and child care programs. Close coordination between and integration of health care and developmental services is critical. Partnerships should attempt to enhance the competence of families to develop and strengthen lasting networks of natural support.*

Family Centered: *A family centered approach places the whole family as the focal point for supports. Evaluation, planning and services are based upon the uniqueness of the family and its culture. Strategies for promoting a child's development are integrated into the family's daily activities and routines and strengthen the role of family members.*

Natural Environments: *Services and supports should occur in settings most natural and comfortable for the child and the family. They should foster opportunities for the development of peer relationships with children without disabilities. Home-based intervention and inclusive community group settings are preferred. The unique characteristics of the family's community - and the development of a natural system of supports within that community - should be promoted at all times.*

Best Practice: *Services and supports should reflect the current values for best practice accepted in the field of early intervention in order to yield the most positive outcomes. Interventionists and families should work in teams, sharing their knowledge and skills, communicating, planning and collaborating with each other. Plans should be outcome oriented and understandable by families. They should be based on developmentally appropriate practices geared to the individual needs of the child. Transitions should be well planned and collaborative in nature. The knowledge about best practice is always increasing. Therefore, service provision should be based on the most accurate and recent research available.*

Respect & Choice: *Recognition and inclusion of the knowledge, beliefs, aspirations, culture and preferences of families should be a cornerstone of all planning and delivery of supports and services. Professionals should openly share roles and assist one another in expanding competencies. Teamwork, wherein the family is an important participant, should guide all decisions. Families should be provided with opportunities to choose programs whenever possible. Their satisfaction with services should be an important factor in selecting and evaluating providers of support.*

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Appendix Two

Survey Results

The following are survey results from 34 of the 38 Connecticut Birth to Three programs. At the time of the survey, of the 3622children enrolled in the Birth to Three System 269 children were receiving some form of nutrition services while being served by one of these 34 Birth to Three programs.

Question	# of Responses
1. Who provides nutrition services for your program?	
Licensed Dietitian/Nutritionists	19
Occupational Therapist	6
Nurse	3
Infant Feeding Specialist	1
Speech Pathologist	1
WIC staff	2
Home Economics Teacher	1
Other Staff not specified	8
2. How does your program determine the need for nutrition services?	
Parent request	32
Interview at evaluation	11
Physician request	9
Staff request	10
Medical profile/condition	4
Screening tool	1
3. What are the types of parent support/training provided on nutrition?	
Parent Groups	8
Individual Discussions with Families	13
Topic at parent group	8
Articles/handouts	7
Workshops/ Inservices	3
Connect with Community Resources	4
None/Minimal	8
4. What are the types of staff support/training provided on nutrition?	
Inservices to staff	10
Consultation	10
Conference attendance by staff	7
Books/Articles	5
None	6
5. What are your program's needs for support in the area of nutrition?	
None/No answer	10
Basic Training	13
Resources in English & Spanish	7
Advisement on when to seek nutrition services	3
Coordination of services	1

Appendix Three

Glossary

Anaphylactic Reaction – a severe allergic reaction of a child to a food or environmental substance.

Aspiration – the act of inhaling food, fluid or saliva into the lungs.

Body Mass Index (BMI) – a ratio of weight and height; a measure of body fat; a marker of nutritional status. To determine the BMI for a child 1) Divide weight in pounds by 2.2 = weight in kilograms, 2) divide height in inches by 39.4 = height in meters, 3) multiply height in meters by itself = height in meters squared, and 4) divide the weight in kilograms (first step) by the height in meters squared (third step) = BMI.

Bolus – term to indicate feeding being given at one time, usually by gastrostomy or nasogastric tube feeding; volume is generally specified.

Bronchopulmonary Dysplasia (BPD) – a form of lung disease seen in infants, the majority premature. Signs of respiratory distress such as chest retractions, crackles and wheezing characterize disease.

Catch Up Growth – growth suppression can occur from malnutrition or illness. During the recovery phase, a child can grow at a rate above that expected for age. As the more rapid growth proceeds, the child "catches up" to his/her growth curve.

Colitis – inflammation of the colon.

Corrected Age – in premature infants, this is the age the child would be if he or she had been born at full term.

Cystic Fibrosis – an inherited disease that affects the secreting glands. Children with cystic fibrosis have difficulty with digestion and breathing as the result of thick, sticky mucous which often clogs up the glands.

Failure to Thrive – term used to describe infants and young children with malnutrition. Commonly used criteria include: 1) a child whose weight (or weight to height) is less than two standard deviations below the mean for sex and age, 2) a child whose weight curve has crossed more than 2% lines on the National Center Health Statistics (NCHS) after having achieved a previously stable pattern.

Galactosemia – an autosomal recessive disorder characterized by the body's inborn inability to metabolize galactose (a sugar substance derived from lactose, i.e. milk sugar). This causes high levels of galactose and, if untreated, results in liver and kidney disease, cataracts, and mental retardation.

Gastroesophageal Reflux (GER) – movement of stomach contents upward through the lower esophageal sphincter; results in uncomfortable, burning sensation; common cause of feeding and eating problems in infants and children with neuromuscular disabilities.

Gastrostomy – surgical creation of a gastric tube-like passage through the abdominal wall, for introducing food into the stomach.

Human Milk Fortifier – powder added to pumped breast milk to increase protein, vitamin and mineral content for premature babies.

Hypoallergenic Formulas – group of infant formulas that are based on hypoallergenic protein source consisting of amino acids and small peptides. They are particularly useful when there has been damage to the infant's GI tract, usually resulting from a viral or bacterial infection.

Jejunostomy – the surgical creation of a permanent opening to provide feeding directly into the small intestine.

Ketogenic Diet – high fat, low carbohydrate diet given to young children with seizure disorders who do not respond well to drug therapy.

Phenylketonuria (PKU) – the most common of the inborn errors of metabolism. The amino acid/phenylalanine cannot be used properly in an inherited metabolic disorder.

Prader-Willi Syndrome – a genetic disorder characterized by inability to distinguish hunger from appetite, short stature, and moderate to severe developmental delays. If not treated by calorie restriction and restricted access to food, individuals with this condition develop severe obesity.

Recommended Daily Allowance (RDA) – the RDAs are standards against which the nutrient intake of normal healthy children in the U.S. can be evaluated. They are based on the average daily amount of nutrients that healthy population groups should consume over time and are not requirements for the individual.

Short Bowel Syndrome – inadequate absorption of ingested nutrients due to a surgical procedure in which a considerable length of the intestinal tract has been removed or bypassed.

Soy Formula – group of infant formulas made from soy protein isolates.

Suckling – reflex coordinating swallowing and breathing during feeding in which the tongue moves forward and back; generally the first feeding pattern in infants; replaced by sucking.

Tongue Lateralization – ability to move the tongue voluntarily from side to side from its midline position; developmental stage in feeding that signals the ability to manipulate food inside the mouth and to protect the airway.

Weight to Height Ratio – assessment of body weight in proportion to height thereby distinguishing wasting from dwarfism. Ideal body weight (50%) represents appropriate body weight for height: weight/height <5th percentile or >90th percentile should be further evaluated.

Resources

Programs, Agencies, and Companies

Child Nutrition Programs has training materials available for loan. For a catalog, call (860) 807-2075 or write to:

Connecticut State Department of Education – Child Nutrition Programs
25 Industrial Park Road
Middletown, Connecticut 06457-1543
(860) 807-2083

Children with Special Health Care Needs (Title V) promotes and provides early identification, early intervention and rehabilitative services for eligible children who are medically vulnerable or are affected by handicapping conditions and whose families are medically indigent. Contact the Department of Public Health in Hartford at (860) 509-8074 or contact the center at the Connecticut Children's Medical Center at (860) 545-9230 or the center at Yale at (203) 737-5462.

Connecticut Association for Human Services, (CAHS) is a private, nonprofit research, education and advocacy organization dedicated to making the human services system work on behalf of all Connecticut's citizens. CAHS includes a number of divisions. Of interest is the Hunger Division, which staffs the Connecticut Anti-Hunger Coalition (CAHC), 110 Bartholomew Avenue, Suite 4030, Hartford, CT 06106-2201. New Haven, CT Office: (203) 752-1219, Hartford, CT Office: (860) 951-2212.

Medela, Inc., has information on the Haberman feeders, S&S feeding systems, and breast pumps or see website on next page. Contact them at P. O. Box 660 McHenry, IL 60051-0660, phone (800) 435-8316, fax (815) 363-9941.

Special Supplemental Nutrition Program for Women, Infants and Children (WIC) has been in operation since 1974. The program is funded by the United States Department of Agriculture, and is administered by the State of Connecticut, Department of Public Health. The Department of Public Health contracts with local agencies to operate the program. There are 21 local agencies and 57 satellite sites throughout the state. The local agencies consist of local health departments, hospitals, community health centers, and community action agencies. The program provides nutrition education and referrals to other health and social services to eligible families. In addition, they provide nutritious foods such as milk, eggs, cheese, dried beans, peanut butter, cereals and infant formula. WIC Hotline: (800) 741-2142.

U.S. Department of Agriculture, should be contacted by any person who feels he or she has been discriminated against in any U.S. Department of Agriculture activity, including Child Nutrition Programs. Contact USDA, Director, Office of Civil Rights, Room 326-W, Whitten Bldg., 14th and Independence, SW, Washington, D.C. 20250-9410. (202) 720-5964 voice or TDD.

University of Connecticut, Cooperative Extension System provides education and materials to agencies and consumers on topics such as agriculture, horticulture, water quality, human development, 4H youth program and nutrition. Nutrition specialists are housed in several extension offices throughout the State (West Hartford, North Haven, Norwich and Storrs) and provide training and materials on a variety of food and nutrition topics including breastfeeding, infant and child nutrition and food safety. Services are provided free of charge. Contact them at the College of Agriculture and Natural Resources, 1800 Asylum Avenue, West Hartford, CT 06117 (860) 570-9010.

Publications

A Food Guide for the First Five Years. Natural Livestock and Meat Board, Beef Promotion and Research Board, 1996.

Breastfeeding: Nature's Best for You and Your Baby. Stacy, L. and Mizumoto, D., The American Dietetic Association, 1993.

"Breastfeeding the Infant with Special Physical and Developmental Needs". Gartner, S., *Nutrition Focus*, University of Washington, July/August, 1996. (206) 685-1297. Back issues are $5.00 each.

Breastfeeding the Infant with Special Needs. Nursing Module, March of Dimes. Provides "hands-on" clinical support techniques for breastfeeding infants with cleft lip and palate, neurological disorders, cardiac disorders and infants born prematurely. Item #33-779-97. $15.00. Fulfillment Center (800) 367-6630.

Children with Special Health Care Needs: A Community Nutrition Pocket Guide. 1997. Dietetics in Developmental and Psychiatric Disorders and the Pediatric Nutrition Practice Group of the American Dietetic Association, Ross Products Division of Abbott Laboratories, USA.

Cross-Cultural Counseling – A Guide for Nutrition and Health Counselors. September, 1986. United States Department of Agriculture, United States Department of Health and Human Services.

Early Start Manual: Nutrition Services in Early Intervention. The manual describes a system for the delivery of nutrition services to children and families within Early Intervention Programs. These services include nutrition screening, assessment, intervention, monitoring and support as routine components of care. Available through AHEC – Gail Lewis, 55 Lake Avenue North, Worcester, MA 01655.

Environmental Nutrition. July 1998, Volume 21, Number 7, Page 2. Institute of Pediatric Nutrition – free information on pediatric nutrition (800) 721-5222.

Feeding and Nutrition for the Child with Special Needs, Handouts for Parents. Klein and Delaney. Breastfeeding basics, tips for expressing and storing breast milk, 1990.

Feeding Your Baby. Center for Craniofacial Anomalies, Chicago, IL. (312) 996-7546. $1.75.

Nursing Your Baby with Down Syndrome
Nursing Your Baby with Cleft Lip and Palate
Nursing Your Premature Baby
Nursing Your Neurologically Impaired Baby
All booklets available from Childbirth Graphics (800) 299-3366 ext. 287, and can be purchased singly or in bulk. One to nine copies are $2.00 each, a set of four, $5.00.

Nutrition Care for the Premature Infant after Discharge from the Hospital. *Nutrition Focus*, Jan./Feb. 1993, University of Washington, Seattle. (206) 685-1297. Back issues $5.00 each.

Nutrition Know-how for Children Ages 1-5 Years Old. Kellogg Company, Battle Creek, Michigan, 1994.

Parent Eating and Nutrition Assessment for Children with Special Health Care Needs, PEACH Survey. Campbell, M. and Kelsey, K., 1993. Copies are available from the Children and Youth Section, Division of Maternal and Child Health, P.O. Box 27687, Raleigh, NC 27611.

Premature and Low Birth Weight Infants Have Special Nutritional Needs (handout), The Institute of Pediatric Nutrition, (800) 721-5222.

Articles and Books

Arvedson, Joan and Brodsky, Linda. *Pediatric Swallowing and Feeding Assessment and Management*. San Diego, CA., Singular Publishing Group, Inc., 1993.

Ekvall, Shirley W., *Pediatric Nutrition in Chronic Diseases and Developmental Disorders*. New York. Oxford University Press, 1993.

Guide to Your Child's Nutrition. American Academy of Pediatrics, 1999, (800) 433-9016.

Huggins, K., *The Nursing Mother's Companion*. Harvard Common Press, Boston, MA, 1996.

Jelm, Judy Michels, MS CCC-SLP, *Oral-Motor/Feeding Rating Scale*. Therapy Skill Builders, 1998, (800) 211-8378.

Kedesdy, Jurgen H., Ph.D. and Budd, Karen S., Ph.D. *Childhood Feeding Disorders – Biobehavioral Assessment and Intervention*. Brookes Publishing, 1998.

Kessler, David B. and Dawson, Peter, *Failure to Thrive and Pediatric Undernutrition*. Baltimore, MD. Paul H. Brookes Publishing Company, 1999.

Klein, Marsha Dunn, M.Ed., OTR/L and Delaney, Tracy A., Ph.D., R.D., *Feeding and Nutrition for the Child with Special Needs – Handouts for Parents*. Therapy Skill Builders, 1998, (800) 211-8378.

Morris, Suzanne Evans, Ph.D. and Klein, Marsha Dunn, M.Ed. OTR. *Pre-Feeding Skills*, Therapy Skill Builders, 1987.

Pediatric Nutrition Handbook. Fourth Edition. American Academy of Pediatrics, 1998, (800) 433-9016

Preventive Health Care for the Premature Infant. Pediatric Rounds. Volume 3, Number 3, August, 1994.

Queen, Patricia M. and Lange, Carol E., *Handbook of Pediatric Nutrition*. Gettysburg, Maryland. Aspen Publishers Inc., 1993.

Subcommittee on Nutrition During Lactation, Institute of Medicine, Food and Nutrition Board, National Academy of Science, monograph, National Academy Press, Washington, D.C., 1991.

Tamborlane, William V., *The Yale Guide to Children's Nutrition*. Yale University, 1997.

Thomas, C. L., (ed), *Taber's Cyclopedic Medical Dictionary*. Edition 17, F. A. Davis Company, Philadelphia, 1989.

The Early Intervention Dictionary: A Multidisciplinary Guide to Terminology. Coleman, Jeanine G., Woodbine House, 1993.

Wold, Lynn S., MOT, OTR and Glass, Robin P., MS OTR, *Feeding and Swallowing Disorders in Infancy – Assessment and Management*. Therapy Skill Builders, 1998, (800) 211-8378.

Websites

American Academy of Pediatrics This site includes two areas of interest: AAP's position on a range of issues, in language suitable for distribution to parents and a parent's resource guide listing books, magazines and videos of interest to parents. www.aap.org (Go to Policy Statements – Education Resources Guide).

American Medical Association – www.ama.assn.org This site provides access to an extensive list of Journals including Archives of Pediatric and Adolescent Medicine.

Connecticut Association of Human Service Agencies and Kaiser Permanente – www.kidsfood.org This site provides food activities for children, parents, and teachers.

Breastfeeding Website – www.bflrc.com/links.htm lists nearly 100 organizations that support breastfeeding.

Healthtouch – www.healthtouch.com This site contains parent/patient counseling materials on a number of nutrition related topics, including: "Facts About Feeding Your Baby"; "Feeding Newborns"; and "When Should Babies Eat Solid Food?" (*Click on "Health Information"*). The American Dietetic Association has authored much of the material at this site.

Medela website – www.medela.com Information on Haberman feeders and S&S feeding systems and breast pumps.

National Center for Health Statistics – www.cdc.gov/nchs/nhanes.htm (See Public Health Interests items – Growth Chart). This site talks about the revised growth charts.

North American Society for Pediatric Gastroenterology and Nutrition – www.vtmednet.org This site contains both patient and professional information. It also includes a list of over 20 organizations prepared to answer questions and supply information on various gastrointestinal conditions.

New Visions – www.new-vis.com This site offers useful, practical information on feeding, oral-motor skills, and mealtimes as well as access to their catalog on oral motor, feeding, and mealtime programs.

Tips for Using the Food Guide Pyramid for Young Children 2 to 6 years Old, a 16-page booklet that includes the adapted pyramid graphic and accompanying information on good nutrition for children. Available to the public on USDA's Center for Nutrition Policy and Promotion Internet home page at www.usda.gov/cnpp or through the Government Printing Office by calling (202) 512-1800.

www.nal.usda.gov/fnic to obtain food pyramids for different cultural groups, contact the USDA's web site.

Local Specialized Resources For Breastfeeding

Center for Craniofacial Anomalies, CT Children's Medical Center, (860) 545-9360. Breastfeeding support for infants with cleft lip and palate.

Yale New Haven Hospital Breastfeeding Support Program and Telephone Information Line, New Haven, CT (203) 688-6865. Infoline, support groups, nurse lactation counselors, breast pumps, SNS and Haberman feeders. Certified Nurse Lactation Consultants can provide expertise for infants with special needs.

General Breastfeeding Support And Information

The Lactation Center at Hartford Hospital, (860) 545-2824. Provides lactation consultants, breastfeeding support group, written information, breast pump rentals, etc.

La Leche League – Helpline (860) 563-6624. La Leche League offers mother to mother support in communities throughout Connecticut and breastfeeding literature.

March of Dimes Connecticut Chapter, East Hartford, CT (860) 290-5440.

Connecticut Birth to Three System

Appendix Five

BIRTH TO THREE NUTRITION SCREENING

Child's Name: _____ D.O.B. _____ Date of Screening _____
Age: _____ Parent / Caregiver: _____
Address: _____ Date: _____
_____ Tel. No. _____

Health / medical condition: _____
Service Coordinator _____

To the parent or questioner: Circle or check the correct answer or answers.

1. How does your child eat? Check choices below that best describe how.
   - __ uses bottle
   - __ breastfeeds
   - __ takes sips from a cup
   - __ drinks from a cup with/without lid
   - __ uses a straw
   - __ takes oral feeding supplements (Pediasure®, Boost®, Kindercal®, and Neocate®)
   - __ has feeding tube
   - __ finger feeds
   - __ fed by spoon
   - __ self-feeds with spoon/fork
   - __ uses special feeding equipment, what?
   - __ takes foods other than milk from a bottle

2. Do you have any concerns about whether your child is eating at an appropriate stage for his age?
   ☐ No ☐ Yes

3a. Are you concerned about the amount or variety of foods your child takes in from the following food groups?
   ☐ No ☐ Yes *(If yes, check all that apply)*

   - __ milk and dairy foods
   - __ vegetables
   - __ breads, cereals, rice, beans, and grains
   - __ snack foods (chips, soda etc.)
   - __ meats, eggs, fish, poultry
   - __ fruits
   - __ fats
   - __ sugars/sweets

3b. Please note any dietary restrictions in your child's diet:

4. Do you or your doctor have concerns about your child's size? No Yes *(If yes, explain)*
   Child's latest length_____weight_____

5. Does your child have food allergies? ☐No ☐Yet *(If yes, list)*

6. Does your child take any medications or other supplements (vitamins, iron, fluoride, or herbal supplements) on a regular basis? ☐No ☐Yes *(If yes, list)*

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7. Does your child experience any of the following: ☐No ☐Yes (*If yes, check all that apply*)

__ difficulty with sucking
__ difficulty with swallowing
__ difficulty with chewing
__ difficulty tolerating food textures
__ difficulty tolerating food temperature
__ choking
__ diarrhea
__ constipation
__ vomiting/reflux
__ rashes
__ gagging
__ other:

8. Do you have concerns about your child's mealtime experiences and eating behaviors? ☐No ☐Yes

If yes, check the choices below:

__ child refuses to eat
__ child spits out food
__ child throws food or utensils
__ child eats too slowly
__ child stuffs mouth
__ child takes bottle to bed
__ no scheduled mealtimes
__ child unable to sit through meal
__ mealtimes are hectic
__ meal seems to take too long
__child eats items, which are not food, (i.e. paint chips, crayons, dirt, paper, cigarettes, etc.)

9. Has your child ever had a history or diagnosis of any of the following: ☐No ☐Yes *(If yes, check all that apply)*

__ AIDS/HIV
__ Autism
__ Bronchopulmonary Dysplasia
__ Cardiac Problems
__ Cerebral Palsy
__ Cleft / Lip or Palate
__ Congenital Heart Disease
__ Cystic Fibrosis
__ Diabetes
__ Down Syndrome
__ Failure to Thrive
__ Fetal Alcohol Syndrome
__ Gastrointestinal disorders
__ Hyperinsulinemia
__ Inborn Errors of Metabolism - Galactosemia, Glycogen storage disease, Phenylketonuria (PKU),
__ Lead Exposure
__ Muscle disorders (MS, Spinal Muscular Atrophy)
__ Myelomenigecele / Spina Bifida
__ Nutrition Support (tube or IV feedings, Other- please specify)
__ Prader–Willi Syndrome
__ Premature birth / Very Low birth weight (VLBW)
__ Renal Disease
__ Seizure Disorder
__ William's Syndrome
__ Other - please specify

IF THERE ARE TWO OR MORE YES ANSWERS FOR QUESTIONS 2-9 THE CHILD IS LIKELY TO HAVE A NUTRITION PROBLEM

10. Do you feel you have enough foods, formula for your child? ☐ Yes ☐ No

11. Would you like to meet with someone about your child's nutrition or eating habits? ☐Yes ☐No ☐Later

ACTIONS TAKEN:

☐ Refer to a nutrition specialist.
☐ Caregiver requests referral to nutrition specialist.
☐ No nutrition intervention needed at this time. Recheck again _____.
date
☐ Is currently receiving nutritional services from _____
These services are:_____
_____
☐ Nutrition services included as early intervention service in IFSP.

Completed by: _____ Title:_____
Date: _____

Appendix Six

Formulas

Formulas for infants and toddlers may be divided into categories. The following categories and examples of some commercial products are listed here for informational purposes. Since this information may change, parents should contact their pediatrician or nutrition specialist for current information and the best formula for their child's age and needs. The use of these products in this document does not imply any endorsement by the Connecticut Birth to Three System.

Amino acid-based formulas
Examples: Neocate®, EleCare®
Nonallergenic
May be appropriate for infants with cow's milk protein intolerance, multiple food protein intolerances, reflux esophagitis associated with symptoms of formula intolerance and growth failure.

Casein hydrolysate formulas
Examples: Alimentum®, Nutramigen®, Pregestimil®, Portagen®
Hypoallergenic
May be appropriate for infants and toddlers with damage to the GI tract, malabsorption problems, and carbohydrate intolerance.

Cow's milk-based formulas
Examples: Enfamil®, Similac®

Hydrolyzed whey-based formulas
Example: GoodStart®
Not the same as hypoallergenic formulas. May be appropriate for infants with a family history of allergies or those progressing from hypoallergenic formulas.

Nutrient dense formulas for children 1 Year or older.
Examples: Pediasure® (with and without added fiber), Kindercal®, Nutren Junior® (with and without added fiber), Resource®
Just for Kids for children one year and older, all are lactose free, but contain milk protein.

Soy-based formulas
Examples: Isomil®, Prosobee®, Nursoy®
All soy-based formulas are lactose free.

Transitional premature formulas
Examples: NeoCare®, Enfamil 22®
Provides nutrition for the first full year to assist with catch up growth.

Appendix Seven

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