Community Based Nutrition Services for Children with Special Health Care Needs in Spokane County, Washington

August 2006



Division of Prevention and Community Health Washington State Department of Health 310 Israel Road SE PO Box 47880 Olympia, WA 98504-7880

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Written by:

Janet Gilliam, MS, RD, CD and Sandra O. Laney, RD, CD Spokane Regional Health District Children with Special Health Care Needs Program

Yuchi Yang, MS, RD, CD Children with Special Health Care Needs Program Washington State Department of Health

Data analysis performed and documents by: Virginia Sharp, MA Center for Children with Special Needs Children's Hospital and Regional Medical Center

Reviewed by:

Maria Nardella, MA, RD, CD and Civillia Winslow Hill, RHIA Children with Special Health Care Needs Program Washington State Department of Health

Betty Lucas, MPH, RD, CD and Sharon Feucht, MA, RD, CD Center on Human Development & Disability University of Washington

Ulrike Kaufmann, RN, BSN Children with Special Health Care Needs Program Spokane Regional Health District

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Introduction

Children with special health care needs are defined by the federal Maternal and Child Health Bureau (MCHB), Department of Health and Human Services, as "those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions, and who require health and related services of a type or amount beyond that required by children generally "(1). Medical diagnoses include such conditions as asthma, attention deficit hyperactivity disorder (ADHD), mental health issues, cerebral palsy, cleft lip and palate, Down syndrome, spina bifida, autism spectrum disorder, congenital heart disease, developmental disabilities and others. In this study, children who are "at risk" include those with one or more of the following characteristics: low birth weight, premature birth, or prenatal substance exposure.

The National Survey of Children with Special Health Care Needs conducted by the National Center for Health Statistics in 2001 indicated that 12.8% of the nation's children and 13.7% of Washington State children had special health care needs based on the MCHB definition (2). These prevalence estimates do not include "at risk" children; only those who already experience consequences of their special health needs were identified.

Children with special health care needs frequently have nutrition problems. Common nutrition concerns include growth alterations (underweight, overweight, or short stature), feeding difficulties, nutrient-drug interactions, food intolerances or allergies, constipation, the need for special diets, dental disease, and partial or total dependence on enteral or parenteral nutrition. One survey estimated that 40% of infants and children with special health care needs have nutrition risk factors that indicated referral to a registered dietitian (RD) (3). A survey of children from birth to age three years, with developmental delays in early intervention programs, found 79% to 90% had one or more nutrition risk factors (4).

Nutrition services are essential to meeting the health needs of children with disabilities and chronic conditions. The goal of nutrition assessment and intervention is healthy, alert and interactive children who can participate in activities at home and in the community. A child who is well-nourished has increased alertness and attention span and the energy to participate in educational activities and social interactions. For a child with special health care needs, adequate nutrition may mean fewer absences from school and therapies, and decreased need for physician visits and hospitalizations.

Federal legislation has impacted the delivery of health care services to children with special health care needs. Title V of the Social Security Act authorized Maternal and Child Health (MCH) services in 1935. MCH and Crippled Children's Services Programs were consolidated into a single MCH Block Grant in 1981. In 1986, programs for Crippled Children were renamed and redefined as Children with Special Health Care Needs (CSHCN) programs. The Omnibus Budget Reconciliation Act of 1989 designated a minimum of thirty percent of each state's block grant funding be used for children with special health care needs and their families. Children, 17 years of age or younger, are eligible for CSHCN services in Washington State (5). As a result of legislation enacted since 1970, institutions for persons with developmental disabilities were closed or downsized and public schools were mandated to provide education and services for children with disabilities.

In 1991, the Individuals with Disabilities Education Act (IDEA) expanded services to children with special needs from infancy through adolescence including the public school system and early intervention services. IDEA Part C is the early intervention component of the legislation that provides services to children from birth to age three and includes nutrition as a reimbursable service. As a result of IDEA Part C legislation, registered dietitians (RDs) have increased their involvement nationally with early intervention programs for children with special health care needs and their families (6). Nutrition services are often provided in a community setting such as in the home, child care facility, Head Start program, or early intervention program. Registered dietitians work with interdisciplinary teams including teachers, speech therapists, occupational therapists, physical therapists, social workers, and others to meet the identified needs of the child and family (7).

The Surgeon General directed programs for children with special health care needs to be family centered, community based, comprehensive, and culturally sensitive in 1989. This goal was adopted as the National Agenda for children with special health care needs by the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services (8). The American Dietetic Association released a position statement on providing nutrition services for infants and children with developmental disabilities and special health care needs: "Nutrition services are essential components of comprehensive care for infants, children and adults with developmental disabilities and special health care needs" (4).

In Healthy People 2010, the MCHB identified key indicators for children with special health care needs to assure improved health outcomes. These outcomes include:

- coordinated ongoing comprehensive care within a medical home for all children
- community-based systems organized so that families can easily access care.

Specific objectives acknowledge the importance of nutrition assessment, counseling and service provision for all populations and call for primary care providers to provide "nutrition assessment and counseling and /or referral to qualified nutritionists or dietitians" (9). Additional objectives call for reduction of growth retardation in children and for an increase in the number of service systems for children at risk for chronic and disabling conditions.

This report presents data collected from 1996–2003 (8 years) on nutrition concerns, services, interventions, and outcomes for 431 children with special health care needs in Spokane County, Washington. The children in this study received community-based nutrition services from registered dietitians (RDs) who had specialized training and were employed by the local CSHCN program. Data collected included demographics, medical and nutrition diagnoses, nutrition interventions, and nutrition outcomes. This report supports the need for early intervention and frequent nutrition follow-up for improving the health status of children with feeding difficulties and underweight issues.

Background

Spokane Regional Health District Children with Special Health Care Needs Program is unique in Washington State in that it employs RDs with specialized training through the CSHCN Nutrition Network to provide nutrition care and intervention to this high-risk population. Many RDs in Washington State, including those employed by the Spokane Regional Health District CSHCN Program, are certified dietitians (CDs) but will be referred to as RDs in this report. The CSHCN Nutrition Network is a group of nutritionists/RDs who have participated in intensive training on the nutrition needs of children with special health care needs at the Center on Human Development and Disability (CHDD) at the University of Washington. The Spokane CSHCN nutrition program provides access to nutrition services for children who meet CSHCN eligibility requirements:

- residents of Spokane County
- birth to age 18 years
- medical eligibility for Washington State CSHCN Program

All families are served regardless of income. There is no charge to the family for nutrition services. Sources of revenue used to pay for CSHCN RD salaries have included state Title V MCH grants, federal Medicaid administrative match funds, and local health district funds.

Almost 20 years ago, Spokane Public Health Nurses (PHNs) working with chronically ill and handicapped children and the regional neuromuscular center identified nutrition as a critical need and an unfilled gap in service. In 1988, the Spokane County Health District requested funding from Washington State Department of Social and Health Services (DSHS), Nutrition Services Section, to hire a public health nutritionist "who will assist with the specific nutritional needs of children with special health care needs". The following year, funding was included in the MCH consolidated contract for Spokane County Health District to correspond with the budgeted amount for a half-time nutritionist/RD. The position was to set a standard for coordination of this type of service in the state. Responsibilities included serving as a member of a multidisciplinary health care team and as a resource person for the eastern side of the state. The person filling this position would also provide direct evaluation, consultation and follow-up nutrition services to children with special needs, coordination of care with other nutrition programs, consultation with PHNs, and education for health care providers.

The Spokane CSHCN Nutrition Program evolved to a full-time position shared by two RDs in 1991. With increased visibility of nutrition services, a growing CSHCN caseload, and the addition of population-based system-focused roles, today the two part-time RDs share hours equivalent to 1.5 FTE. The same RDs have filled the CSHCN nutrition positions since 1990 and 1991. Both RDs attended the 3-day intensive training course on nutrition for children with special health care needs at CHDD. In addition, the CSHCN RDs attend biannual meetings of Washington State Department of Health (DOH) -sponsored CSHCN Nutrition Network meetings at CHDD for updates and trainings.

Sources of referral for children with special health care needs for nutrition services in Spokane include:

- Public health nurses
- Hospital social workers and discharge planners
- Hospital RDs
- WIC staff
- Early intervention providers (including regional neuromuscular center)
- Family Resources Coordinators
- Primary care providers and pediatric specialists
- Community RDs (including those employed by home health agencies)

Public awareness of CSHCN nutrition services comes from an agency brochure, PHN hospital liaison position, Infant Toddler Network provider meetings, PHN and RD networking (the CSHCN RD initiated local pediatric RD networking), Child Health Notes newsletter, and, most recently, from the health district website.

Children who qualify for the CSHCN Program are eligible for nutrition services. Families of children with special health care needs (from birth to 18 years) are assisted in accessing nutrition services based on their child's needs and available resources. A nutrition plan is developed and coordinated with the family, health professionals and others to ensure continuity of nutrition care. Children may be seen by the CSHCN RD or referred to the most appropriate community resources for nutrition services. Children with some diagnoses or conditions are routinely referred to other community providers. For example, children with cystic fibrosis are referred to the Cystic Fibrosis clinic, tube fed clients to community RDs who are employed by home health agencies or durable medical providers, children with diabetes to community diabetes educators, children with cancer to hospital RDs in pediatric oncology, those with eating disorders (anorexia and bulimia) to community specialists, and children with metabolic disorders to the University of Washington CHDD Metabolic Clinic. Other children may be seen at the Sacred Heart Children's Hospital Feeding and Growth Clinic for evaluation and/or short term intervention with follow-up by the CSHCN RDs in the community.

Despite the potential impact of poor nutritional status on growth and development, nutrition services may not be routinely available to this high-risk population. Parents who participated in four focus groups in Washington State identified issues with nutrition services for their children with special health care needs (10). Nutrition services were sometimes difficult to locate and often only initiated after an illness or crisis. Parents agreed that early nutrition intervention would be beneficial for their children. Parents preferred a consistent source for nutrition services to avoid confusion and fragmentation in feeding and nutrition recommendations. Families of children with special health care needs in Washington State indicated that they preferred to receive nutrition intervention from RDs with specialized training who are able to provide services in community based settings (11). Parents believed their children would benefit from access to early nutrition intervention to improve growth and nutritional status and to prevent or reduce potential health risks. Families who received nutrition services from RDs with specialized training in working with children with special health care needs, such as community-based RDs affiliated with local CSHCN programs, expressed a very high level of satisfaction with those nutrition services.

The Washington State DOH CSHCN Program identified gaps in nutrition services for children with special health care needs in a survey of community and pediatric RDs (11). The survey identified the need for additional training of RDs, for strengthening referral networks and for increasing the awareness about the benefits of early and comprehensive nutrition intervention for children with special health care needs. It also concluded that information about the children served, nutrition problems and

interventions, and outcomes would benefit families, health care providers and policy makers.

Health care services for children in the Spokane region grew substantially during the 8 year study period from 1996 to 2003. The CSHCN Program identified a need for nutrition services (home visits) for children with feeding tubes in the early 1990's and advocated for pediatric RDs to be employed by home health agencies to meet that need. The number of agencies in Spokane with pediatric RDs on staff increased from 3 to 6 between 1996 and 2003.

Purpose

Data on the prevalence and nature of nutrition problems is needed to plan services to meet the needs of children with special health care needs. Collection of nutrition assessment data can be used to track progress in meeting desired nutrition outcomes and to help determine the type and extent of nutrition services needed to control, improve or resolve common nutrition and feeding problems.

Purposes of nutrition data collection and analysis in Spokane:

- 1. Describe children who are identified with nutrition problems
- 2. Document nutrition concerns
- 3. Describe type of nutrition services used
- 4. Identify nutrition problems that can be improved with intervention

Methods

Data Collection

Data from the Nutrition Assessment Summary Form CSHCN RDs employed by the Spokane Regional Health District collected data continuously from 1996 through 2003 (8 years) on nutrition services, nutrition diagnoses, and outcomes for all children with special health care needs receiving services. The data were collected using a standardized form (Appendix A). Data were also collected from some other counties but are not included in this report.

CSHCN RDs completed written reports for each nutrition contact at the time of service. The nutrition reports included some or all of the following information:

- Growth data
- Diet history

- Diet analysis
- Nutrition assessment
- Diet instructions
- Nutrition care plan
- A list of other interdisciplinary team members and agencies involved with the care of the child.

Nutrition contacts included:

- Home visits
- Phone consultations
- Interdisciplinary care conferences
- Visits that took place in community settings such as physician offices, early intervention programs, and child care centers.

Under the direction of the Washington Department of Health CSHCN program, it was determined to use the Nutrition Assessment Data Summary Form (Appendix A) to summarize the data from each nutrition contact. The Nutrition Assessment Data Summary Form was originally developed by representatives of Title V agencies for CSHCN in MCH Region IX (Arizona, California, Hawaii, and Nevada) in the 1980's. Initial funding for development of a regional database and nutrition screening tool was provided by a Special Projects of Regional and National Significance (SPRANS) grant awarded by the federal MCH Bureau, Department of Health and Human Services to the University Affiliated Program at Children's Hospital Los Angeles. Following the development of a nutrition screening tool, data elements for nutrition assessment were selected to track progress in meeting desired nutrition outcomes and to begin to determine the types and extent of nutrition services needed to resolve or stabilize a particular nutrition problem.

Once analysis was begun on the Washington data, it was obvious that some of the initial data elements and codes required revision and additional data elements would be useful for analysis. During the course of the data collection period, the following data elements were collected on the Nutrition Assessment Data Summary Form (Appendix A):

- Length of gestation
- Birth weight
- Birth length*
- Breast feeding history*
- Medical diagnoses from medical history
- Nutrition diagnoses determined by CSHCN RD
- Nutrition services provided at each encounter

- Growth data (length or height, weight)
- Outcomes for each nutrition diagnosis determined by CSHCN RD
- Length of visit*

(*Data elements added in 2001)

Copies of these forms were submitted annually to the Department of Health CSHCN Program office for data entry and analysis as a deliverable under the county's MCH Consolidated Contract.

During the eight-year data collection period, the Spokane CSHCN RDs and program staff consulted with state CSHCN Program staff and the analytic consultant at the Center for Children with Special Needs at Seattle Children's Hospital and Regional Medical Center on data collection procedures and proposals for data analysis and report format. In 1999, the data collection form was revised and codes were assigned to the data elements for more efficient collection and input of data. In 2001, birth length, breastfeeding history, and length of visit questions were added and outcomes were defined using specific examples to provide greater consistency in their use with specific nutrition problems. The data set was reviewed by the state CSHCN nutrition consultants for inconsistencies and missing or duplicate data and corrected by Spokane CSHCN RDs. Based on preliminary analysis of the data, changes were made to the following variables:

- Ethnicity: added Multi-ethnicity and Not Recorded (2002)
- Medical Diagnosis: deleted Cancer and HIV and added ADHD and Failure To Thrive (2002). Changed Autism to Autism/PDD and Metabolic Disorder to Metabolic/ Endocrine Disorder (2002)
- Nutrition Services Provided: added Nutrition Coordination and Multidisciplinary Conference (2001)
- Nutrition Diagnosis: added Alternative diet/products, Inadequate fluids, Gastro esophageal reflux, Dental disease, Food insecurity, and Parent-child feeding interactions (2002).

Data collected using the previous form was recoded, to the extent possible, into these new categories for consistency and completeness.

Data from the Child Health Intake Form (CHIF)

Every child who received nutrition services from the CSHCN RDs was enrolled with the Spokane Regional Health District CSHCN program. Local health jurisdictions including Spokane Regional Health District have contract requirements with the Washington State DOH to collect client information on each child enrolled. The CHIF Automated System collects this data. The required data elements include:

- County
- Date of entry into program and annual renewal
- Name of Child
- Zip code
- Date of Birth
- Sex
- Race
- Economic Level
- Third-party pay sources (insurance)
- ICD9 codes (Medical Diagnosis)
- Additional Involvement with various community resources and agencies

Data Analysis

The Center for Children with Special Needs at Seattle Children's Hospital and Regional Medical Center received funding beginning in July 2000 to work with the CSHCN Program to begin analyzing nutrition data. Spokane County RDs continued to submit "Nutrition Assessment Data Summary" forms (Appendix A) through December 31, 2003. All submitted data were entered into the Access 97 database.

Frequencies and cross-tabulations of the Spokane data were performed. Various subsets of the data were exported to either Excel or SPSS [version 11.0 for Windows] for more detailed analysis and/or graphic representation. The specific analyses performed were defined by the state CSHCN Program nutritionist/RD and Spokane County RDs and operationalized by the analyst at the Center for Children with Special Needs.

The CHIF data analysis was performed by the Washington State DOH MCH Assessment Team.

Results

Demographic Data

According to the CHIF data, there were 4,410 unduplicated children with special health care needs served by the Spokane Regional Health District from 1996 to 2003. Among these children, a total of 431 (or about 10%) children received nutrition services, not available from other community providers, from the CSHCN RDs during these years. Two RDs (1.5 FTE) with specialized training in working with children with special health care needs and their families provided nutrition services. Services were provided in community settings including home visits, early intervention programs, child care programs, and other locations as requested by the family and health care team.

Data on how many children were referred out to other community or hospital RDs was not collected. Other community providers who served children with special health care needs in Spokane included RDs with WIC and First Step programs, hospitals, outpatient specialty clinics, and home health agencies. Table 1 compares the gender distribution, age, and race of children served by the CSHCN RDs (n = 431) with those not served (n = 3,979). The distribution of children by gender was about equal although slightly more boys (55%) received nutrition services from the CSHCN RDs than girls. Overall, children in the CHIF database were young, with the majority of children under the age of five. A slightly higher percentage of children age 2 to 4 received CSHCN RD nutrition services and a slightly lower percentage of those age 15 to 17 received nutrition services compared with those that did not receive nutrition services. The children served by the CSHCN RDs were 82 percent Caucasian, reflecting the ethnic make up of the Spokane region. Minority groups with 3 to 4 percent of the nutrition caseload each included Hispanic/Latino and Black/African American. A subgroup of the Caucasian group served but not explicitly identified in the data collection is a significant population of immigrants from countries of the former Soviet Union who settled in Spokane during the data collection period. Overall, the racial distributions were similar between the two groups (children with special health care needs with and without nutrition services).

Table 1. Comparison of Children Served by CSHCN RDs with other Children in Spokane County CSHCN Program, 1996 - 200 Not Served Served by by Nutritionist Nutritionist (n = 431) (n = 3,979) Total						
Gender						
_ Male		. ,	•	(56%)	•	
Female	190	(40%)	1,592	(44%)	1,782	
Age Group (years)						
0-1	133	(31%)	1,292	(32%)	1,425	
2-4	206	(48%)	1,593	(40%)	1,799	
5-9	62	(14%)	579	(15%)	641	
10-14	24	(6%)	324	(8%)	348	
15-20	4	(1%)	190	(5%)	194	
Race/ethnicity						
White	289	(82%)	1,991	(80%)	2,280	
Black	15	(4%)	123	(5%)	138	
Native American	8	(2%)	111	(4%)	119	
Hispanic	15	(4%)	92	(4%)	107	
Asian	11	(3%)	71	(3%)	82	
Other/Unknown	14	(3%)	86	(3%)	100	

Medical Diagnoses

The medical diagnosis variable from the Nutrition Assessment Summary Data form (Appendix A) was collected differently than most other variables in the database. Medical diagnoses were accumulated for each child over the course of their nutrition visits. That is, once a child had been identified as having a particular medical diagnosis (even if at just one of 20 visits), it stayed in the child's record in the nutrition database. Children may have a general diagnosis of developmental delay, and as they are evaluated by multiple specialists and multidisciplinary teams, more diagnoses are identified.

The vast majority (almost 80 percent) of children seen for nutrition problems had at least one medical diagnosis of developmental delay (Figure 1). The diagnosis of developmental delay is a general term used for children who qualify for early intervention services, but may not yet have a specific medical diagnosis. Children with other conditions such as cerebral palsy, chromosomal anomaly, and autism spectrum disorder may also have the diagnosis of developmental delay. Referrals for nutrition services often originated from early intervention providers, PHNs, and Family Resources Coordinators who provided services for children with developmental delays and concerns. The second most frequent group of medical diagnoses was gastrointestinal disorders. About 20 percent of children had a gastrointestinal disorder such as malabsorption, chronic constipation, or gastroesophageal reflux disease (GER). The third most frequent medical diagnosis, high risk child, refers to children who were exposed to substances during gestation. The ten most frequent medical diagnoses identified are listed in Figure 1.

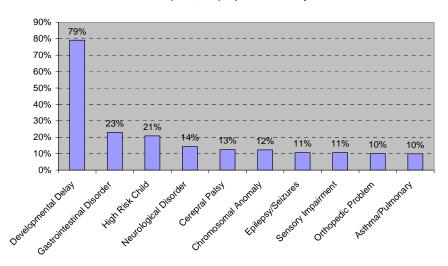


Figure 1: Top Ten Medical Diagnoses for Children Receiving Nutritional Services (N = 1,053), Spokane County, 1996 - 2003

Note: Diagnoses are not mutually exclusive.

Many of the children who received nutrition services had complex medical problems. About 40 percent of the children accessing nutrition services had three or more health and developmental conditions; nine percent had five or more medical diagnoses (Figure 2). The average number of medical diagnoses recorded per child over the study period was 2.6.

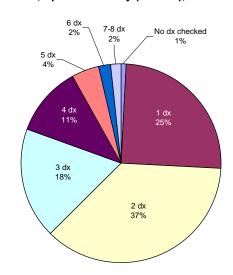


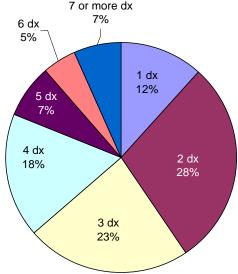
Figure 2: Number of Medical Diagnoses per Child Seen for Nutritional Services, Spokane County (N = 431), 1996 - 2003

Nutrition Diagnoses

The nutrition problems (diagnoses) were accumulated for each child over the course of their nutrition visits. The nutrition diagnoses identified by the CSHCN RDs became the focus for nutrition intervention. Eighty percent had two or more nutrition diagnoses, 36 percent had four or more nutrition diagnoses, and seven percent had seven or more nutrition diagnoses (Figure 3).

Feeding difficulties and underweight were most common nutrition diagnoses in the group of children who received nutrition services from the CSHCN RDs (Figure 4). Sixty-eight percent were identified with feeding difficulties including oral-motor dysfunction, sensory feeding issues, dysphagia, delayed feeding skill development, and/or behavioral feeding problems. Feeding is a complex activity and feeding problems often require interdisciplinary teams to assess and provide appropriate interventions. Feeding dysfunction in children with special health care needs is associated with poor growth and underweight (weight for age below 5th percentile). Underweight was identified in 62 percent of the children receiving nutrition services.





Other common nutrition concerns that may be related to feeding difficulties and underweight were diet inadequacy (35%) and slow growth (28%). Other common nutrition diagnoses included constipation, food intolerance or allergy, partial or total dependence on tube feedings, drug/medication interactions, and gastroesophageal reflux (GER). Overweight was a problem in 12 percent of the children seen by the CSHCN RDs during the study period.

The focus of nutrition interventions mirrored the nutrition diagnoses with feeding difficulties (72%) and underweight (64%) being addressed most often (Figure 5). About 15 percent of children had tube feeding issues. Tube feedings require regular monitoring to adjust calories and avoid complications; therefore, they were the focus of 32% of nutrition intervention. CSHCN RDs also frequently addressed slow growth (28%), diet inadequacy (26%), constipation (20%), and diet/ medication interactions (13%). Nutrition issues, such as feeding difficulties, require long-term follow-up and coordination with other team members and, while feeding abilities may improve, feeding difficulties may never be completely resolved in some children. Other nutrition problems such as nutrient inadequacies may be identified and remedied more easily by recommending use of a nutrition supplement (12).

Figure 4: Top Ten Nutritional Diagnoses Spokane County, 1996 - 2003

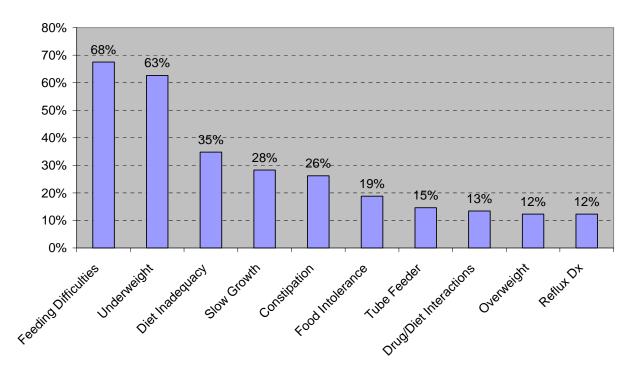
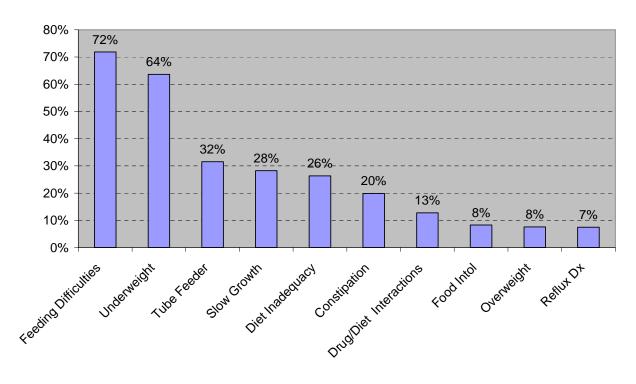


Figure 5: Top Ten Nutrition Intervention Focus Spokane County, 1996 - 2003



Medical Nutrition Therapy (Nutrition Services) Provided

The most frequent types of medical nutrition therapy (MNT) provided were nutrition assessment/ reassessment, monitoring growth parameters, monitoring and adjusting diet, and nutrition education/diet instruction (Figure 6). Anthropometric data was collected by the RD at each visit using standardized techniques and appropriate equipment. In order to address feeding issues, feeding assessments were often done in the home or during oral-motor therapy sessions. Observation of breast or bottle-feeding or a snack or meal in the home provided valuable information about the home environment and parent-child interactions. The CSHCN RDs were trained and certified in the Nursing Child Assessment Satellite Training Feeding Scales (NCAST). NCAST provides a valid and reliable measure of parent-child interaction for children with chronological or developmental ages up to 12 months (13). Its use includes identification of feeding cues. Feeding observation during an oral-motor therapy session allowed team members to share information and give clear consistent instructions to the caregivers.

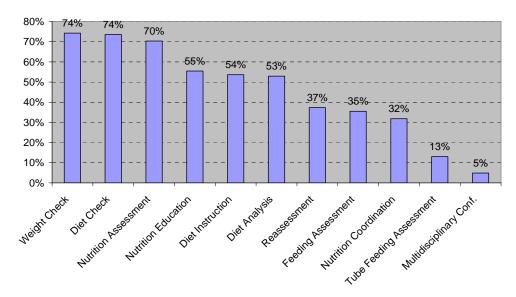


Figure 6: Distribution of Nutrition Services Provided Spokane County, 1996 - 2003

Nutrition Assessment includes:

- Parent/ caregiver concerns
- Anthropometric measurements: length/height, weight, head circumference, triceps skinfold with determination of percentiles for all measurements including weight/length and/or BMI.

- Clinical/ medical history; release of information forms signed by caregivers to obtain and release information to other health care providers working with the child and family.
- Medications, vitamin/mineral supplements
- Complementary and alternative therapies
- Elimination patterns
- Diet history: food record analysis, familial/ cultural food practices
- Tube feedings and oral supplements
- Feeding skills and behavior: feeding/ meal observation
- Oral-motor development, feeding history
- Physical activity level
- Adequacy of food resources

Equipment/Techniques used:

- Infant scale: digital scales measure to .5-ounce increments, calibrated annually. Children under age 3 are weighed without clothing.
- Platform scale for older children, digital scales measure to .5 pound increments, calibrated annually. Children are weighed in light clothing without shoes.
- Measuring mat with rigid head and foot boards, measure to ¼" increments.
 Two-person technique is used to obtain accurate recumbent length measurements.
- Standing height for older children, if appropriate.
- Skinfold calipers
- Nutrition analysis program for tube feedings, infant formulas, and three-day written food records. Food Processor software program is updated annually.
- CDC standardized growth charts (NCHS growth charts were used prior to 2000.)
- Specialized growth charts (such as Down Syndrome growth charts) were used as appropriate
- Age was adjusted for prematurity for up to 36 months.

The complexity of medical and nutrition problems of children with special health care needs requires the involvement of multiple health care providers and community agencies. The CSHCN RDs were often involved in attending multidisciplinary conferences and in coordinating nutrition care between the family and the other team members such as the primary care provider, WIC, home health agencies, early intervention programs, and Medicaid or insurance companies. Care coordination activities include communicating the child's nutrition needs and care plan and advocating for reimbursement for recommended services and products. In Washington State, the Medicaid Medical Nutrition Program requires a nutrition evaluation by a certified dietitian within 30 days of initiation of a medical nutrition product for clients

age 20 and younger. As certified dietitians and Medicaid providers in Washington State, the CSHCN RDs provide documentation of medical necessity for nutrition products (14).

Frequency of Medical Nutrition Therapy

Frequency of visits varied according to the discretion of the RD. Newborns and graduates of neonatal intensive care units often required weekly monitoring, while older babies and children were seen every 1 to 2 months. Children with stable but ongoing nutrition issues were monitored 2 to 4 times per year. Over the course of the data collection period, children entered and exited nutrition treatment as dictated by their nutritional needs, ability to keep appointments, parental interest, and numerous other reasons. No information was collected on reasons for ending treatment and missed appointments.

The total number of nutrition visits per year increased from 1998 to 2001 corresponding with the increase in CSHCN RD hours (Figure 7). Fewer total visits were recorded in 2002 and 2003 due to several changes in the Spokane community. Referral patterns from the two NICU units changed. NICU graduates were routinely referred to Sacred Heart Feeding and Growth Clinic with completion of Sacred Heart Medical Center Children's Hospital. During this same time period, PHN positions were reduced due to reductions in funding for public health. This also resulted in fewer referrals for CSHCN RDs. The number of pediatric RDs employed by community home health/ durable medical companies doubled. Children with feeding tubes were routinely referred to these RDs for nutrition services. Spokane CSHCN RDs took more active roles in helping families coordinate nutrition care between medical providers and community programs, which included the Medicaid enteral nutrition program requirements for nutrition evaluation by a CD.

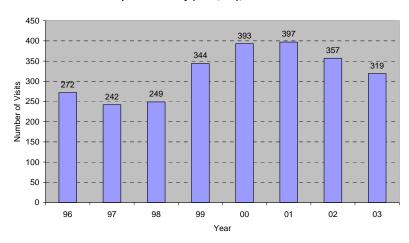


Figure 7: Number of Nutrition Visits by Year Spokane County (N = 2,573), 1996 - 2003

Over the course of the eight-year study period, the number of visits varied from 1 visit to 58 visits per child. Sixty percent of the children seen for nutrition intervention received 1 to 3 visits by a CSHCN RD (Figure 8). About 1 in 6 children (16%) in the sample received 11 or more nutrition contacts during the study period. Six percent received more than 20 contacts by a RD.

The average number of medical diagnoses per child was 2.6 and the average number of nutrition visits per child was 6. Generally speaking, children with more medical diagnoses received more nutrition services. The correlation between the number of medical diagnoses and the number of nutrition visits was .434 which was highly significant.

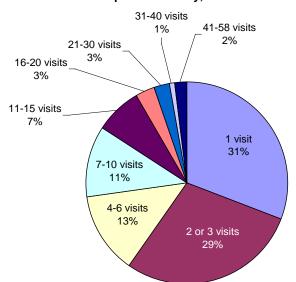


Figure 8: Number of Nutrition Visits per Child Spokane County, 1996 - 2003

Nutrition Outcomes

Nutrition outcomes for nutrition diagnoses were rated for each encounter with each child by the CSHCN RD as resolved, improved, stable, no improvement, or worse. During the initial nutrition visit or when the nutrition problem or diagnosis was first identified, or reoccurred after being resolved, the outcome was coded as "Problem Identified." These outcome codes were defined by the CSHCN RDs using specific examples to improve consistency in their use (Appendix A).

An analysis of data to look at outcomes of last visits based on nutrition diagnoses did not reveal any pattern. There are many factors that may affect outcomes including medical condition, treatments, and family/social environments. In addition, the data collection end date of December 31, 2003 may not represent the end of nutrition service

needs for many of the children. For those children who had already ended their active nutrition treatment, the reason for ending that treatment is unknown. Some may have moved out of the area, some may have transferred to other programs, and others may have come to the conclusion of needed nutrition services.

Nutrition intervention effectiveness varied by condition (Table 2). For the 431 Spokane area children, 228 (16.8%) of the 1358 nutrition diagnoses were recorded as resolved, e.g. achieved and maintained age appropriate incremental weight gain and growth; achieved age appropriate feeding skills; outgrew food intolerance; feeding tube was removed (Appendix A). As Table 2 indicates, some nutrition diagnoses were much more likely to be resolved than others. Over half of all diarrhea diagnoses and almost a third of tube feeding issues were resolved. At the other end of the spectrum, fewer than ten percent of the diagnoses of slow growth and overweight were resolved.

Many variables affect nutrition outcomes. For example, underweight cases were resolved with maturation, medical intervention, or a combination of factors (seizures controlled, ability to tolerate increased volumes of formula, health stabilized). Feeding difficulties resolved with intensive feeding and medical nutrition therapy to address oral motor and swallowing problems and oral hypersensitivity, along with behavioral interventions to address food refusal behaviors, and maturation. In some cases, the child's medical issues were also resolved or stabilized before feeding difficulties could be addressed and resolved.

Table 2. Number and Rates of Resolved Nutrition Outcomes by Nutrition Diagnosis, Spokane County 1996-2003					
Nutrition Diagnosis	Number of Children with Dx	Resolved (#)	% Resolved		
Feeding Difficulties	292	38	13.0%		
Underweight	270	34	12.6%		
Diet Inadequacy	150	35	23.3%		
Slow Growth	122	10	8.2%		
Constipation	113	28	24.8%		
Food Allergy / Intolerance	81 15		18.5%		
Tube Feeding	63	20	31.7%		
Drug/Diet Interactions	58	7	12.1%		
Overweight	53	4	7.5%		
GE Reflux	53	9	17.0%		
Diarrhea	29	17	58.6%		
Special Diet	20	2	10.0%		
Inadequate Fluids	20	3	15.0%		
Anemia	11	3	27.3%		
Parent/Child Feeding Interactions	9	1	11.1%		

Alternative Diet/Products	7	2	28.6%
Dental Disease	5	0	0.0%
Food Insecurity	3	0	0.0%
No. of Nutrition Diagnoses coded for 431 Spokane County CSHCN	1359	228	16.8%

Children with complex medical conditions and multiple diagnoses often have static neurological conditions and medical complications that may not resolve with nutrition therapy. In these children, the goal may be to stabilize the problem and to improve quality of life. Some children with more complex medical conditions, particularly those with cerebral palsy, did not resolve their underweight or feeding difficulties, but were able to improve their underweight status or stabilize feeding difficulties with nutrition intervention.

Outcomes changed frequently in children with complex medical conditions and diagnoses of underweight or feeding difficulties. Some children followed by the CSHCN RD would "improve" in their weight status or feeding abilities at one visit followed by "no improvement" at the next visit. Sometimes the nutrition problem would become "worse" because of medical condition and other factors. One case of underweight showed no improvement after almost 6 years of follow-up due to family and caregiver challenges in following through with RD recommendations. All of the other case studies did show some improvement over time.

Combining nutrition and the CHIF data, 133 (or about 31%) of the 431 children with special health care needs seen by CSHCN RDs had at least one nutrition diagnosis resolved.

Further data analyses were conducted on the two most common nutrition diagnoses: feeding difficulties (68%) and underweight (63%). Among children receiving services from CSHCN RDs for feeding difficulties and for underweight issues in Spokane County, there is no statistically significant association between the number of medical diagnoses and the resolved rates.

From 1996-2003, 13% of Spokane children with special health care needs identified as having a feeding difficulty and 12.6% of Spokane children with special health care needs identified as having underweight issues had their nutrition diagnoses resolved (Table 2). The resolved rates for feeding difficulties and for underweight issues were positively correlated with the number of nutrition visits. Data (Tables 3, 4) showed that children who returned for 5 or more visits were more likely to have their underweight issues resolved [17% vs. 9%] and their feeding difficulties resolved [25% vs. 5%]. Children with underweight issues (N=19) receiving 18 or more visits have over a 31% resolution rate and children with feeding difficulties (N=18) have a 50% resolution rate.

Number of visits and length of time in treatment appear correlated, although we don't know exactly to what extent for this population.

Table 3. Number of Visits by Resolved Rates for Children with Underweight

Issues, Spokane County (N=270), 1996 - 2003

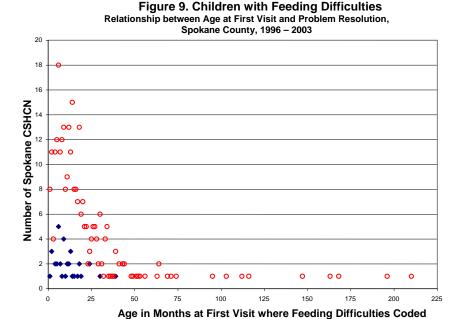
Number of Visits	Total Number of	Number	Resolved Rate
	Children	Resolved	
1 - 4	161	15	9%
5 +	109	19	17%

Table 4. Number of Visits by Resolved Rates for Children with Feeding

Difficulties, Spokane County (N=292), 1996 - 2003

Ī		Total Number of		
	Number of Visits	Children	Number Resolved	Resolved Rate
Ī	1-4	177	9	5%
Ī	5 +	115	29	25%

Children with underweight issues who had received their first nutrition visit before one year of age were more likely to have their issues resolved (20.4% versus 7.7%) (Table 5). Children with feeding difficulties (Figure 9) who had received their first nutrition visit before two years of age were also more likely to have their issues resolved (16% versus 3%). Therefore, it is important to identify these nutrition problems and refer the children to RDs as early as possible.



of children by age at first visit who eventually had feeding difficulties resolved
 Total # of children by age at first visit

Table 5. Children with Underweight issues: Relationship between Age at First Visit and Problem Resolution, Spokane County, 1996 - 2003

Age at First Visit	# Children	# Resolved	Resolved Rate
0-12 mos.	103	21	20.4%
12 mos. +	167	13	7.7%

Discussion

Children with special health care needs in this study who were followed by the CSHCN RDs were a diverse group and often had complex medical and nutrition needs. A majority of the children in this study had multiple medical diagnoses and nutrition problems. Two out of three children receiving nutrition services had feeding difficulties and over 60 % were underweight. Providing medical nutrition therapy for these children is often complicated because many factors interact to affect nutritional status. In order to improve nutrition outcomes, CSHCN RDs coordinated care and consulted with professionals from a variety of disciplines. The multidisciplinary team often included the family and child, primary medical care provider, occupational therapist, physical therapist, speech language pathologist/ therapist, behavior specialist, social worker, Family Resources Coordinator, public health nurse, teacher, home health care providers and others. Other community agencies such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), Head Start, early intervention providers, schools, hospitals, specialty clinics, child care, Division of Developmental Disabilities, and Child Protective Services may also have been involved. Using the team approach, the CSHCN RDs and other involved professionals worked in a family centered partnership to coordinate services and provide continuity of care.

Many nutrition problems were stabilized, improved or even resolved with nutrition interventions by the CSHCN RDs. Nutrition interventions used include the following:

- Adjusting the caloric density of foods or recommending nutrition supplements to achieve and maintain appropriate incremental weight gain, body weight and BMI:
- Altering dietary intake or using a dietary supplement to provide more optimal nutrient intake;
- Altering timing of meals / feedings to reduce side effects and interactions with medications;
- Thickening liquids or modifying texture of foods to improve feeding and swallowing abilities (per recommendation of speech or feeding therapist);
- Increasing fluids and fiber intake to alleviate constipation;

- Altering diet to avoid food intolerances and allergy symptoms;
- Reviewing precautions for reflux;
- Providing breast feeding/ lactation education;
- Teaching or restating instructions to improve compliance with therapeutic diets.

Some nutrition interventions are designed to prevent problems by identifying increased risk for nutrition problems. These include education about dental disease related to delayed weaning from the bottle, risks or disadvantages of some alternative dietary products or complementary therapies, feeding cues and the division of responsibility to promote healthy feeding relationships, and identifying and referring to community resources to assist with providing food and medical nutrition products for the child and family. The CSHCN RDs may also be the first to educate the family about supplemental or alternate feeding therapies such as tube feedings. When nutrition interventions did not resolve or improve the problem, CSHCN RDs consulted with and referred families back to the child's primary medical provider for medical evaluations and interventions for conditions such as persistent gastroesophageal reflux, chronic constipation, unresolved diarrhea, and suspected food allergy symptoms.

A series of case studies revealed that some children with complex medical conditions including cerebral palsy and other static neurological conditions needed regular and long term intervention, monitoring and support by the RDs/CDs (15). In most cases as the child matured and/or health problems resolved, the nutrition outcomes also improved. Even with improved outcomes such as weight gain or achievement of acceptable weight status (BMI), regular monitoring by a RD is still necessary to address changes in health status, medications, and growth patterns to assure nutritional needs are met.

Conclusions

Spokane CSHCN RDs saw 431 children with special health care needs and provided these children with a total of 2,573 community-based nutrition visits between 1996 and 2003. One hundred and thirty three (or about 31%) of the 431 children with special health care needs seen by CSHCN RDs had at least one nutrition diagnosis resolved.

Effectiveness of nutrition intervention varied with different nutrition diagnoses. Feeding difficulties and underweight were the two most common nutrition diagnoses in this project. Early identification and nutrition referral to CSHCN RDs were important. Children in this project with feeding difficulties or underweight issues who received their first nutrition visit early in life were more likely to have their issues resolved.

Frequent nutrition follow-up visits were also important for resolving feeding difficulties and for improving underweight status. For both nutrition diagnoses, the resolved rates were positively correlated with the number of nutrition visits.

Recommendations

Based on the combination of the findings from this study and on the experiences of leaders in the field of pediatric nutrition, we recommend the following for providing community based services for children with special health care needs:

- 1. Nutrition services need to be family-centered. Families are recognized as the experts on the care of their children and need to be included in developing the nutrition care plan.
- 2. Nutrition services are most effective when provided as part of a multidisciplinary team approach. Children with special health care needs have nutrition and medical problems that are often complicated and interrelated. They require the expertise of many disciplines to work together as a team and coordinate care across disciplines and systems.
- 3. Nutrition services must be available and easily accessible for families. Issues include stable funding and reimbursement for nutrition services, accessible locations and flexible hours for busy families.
- 4. Nutrition services should be provided by registered dietitians (RDs) with special training in working with families with children with special health care needs. Training includes: nutrition interventions for children with special health care needs, cultural awareness, community nutrition programs and resources for families, and public health competencies in helping families access nutrition services and medical nutrition products and in advocating for community based nutrition services.
- 5. Nutrition services provide early recognition and intervention of nutrition risk factors and problems. Ideally, all children with special health care needs should be screened as early as possible for nutrition risk indicators and referred for assessment and intervention if indicated.
- 6. Frequent nutrition follow-up visits are necessary to improve the outcomes for certain nutrition concerns such as feeding difficulties and underweight issues.
- 7. Additional research is needed to document positive health outcomes and cost savings from nutrition intervention for children with special health care needs.

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Appendix A. Children with Special Health Care Needs NUTRITION ASSESSMENT DATA SUMMARY

NUTRITION ASSESSMENT DATA SUMMARY Clinic Code:						
County Code: Entry Code:						
Patient Name:	CSHCN #:					
Patient Zip Code:	Sex: Female 🗅	Male □ Date of	Birth:/_	/		
Premature? Yes ☐ No ☐ Breastfed? Yes ☐ No ☐		s Birth we s Birth ler	eight: ngth	gm/ lb cm/ in		
Ethnicity (check one)	Medica	al Diagnosis (Chec	k all that appl	<u>y)</u>		
1 Caucasian 2 Hispanic/Latino 3 Native American 4 African American 5 Southeast Asian 6 Asian 7 Pacific Islander 8 Native Hawaiian 9 Unknown 10 Other 11 Multi-ethnicity 12 Not recorded	□ ADHD □ Asthma/Pulmonary □ □ Autism/ PDD □ B.P.D □ Cardiac Disease □ Cerebral Palsy □ Chromosomal Disord □ Craniofacial Anomaly □ Cystic Fibrosis □ Developmental Delay □ Epilepsy/Seizures □ FTT	☐ Metab ☐ Muscu ☐ Neuro ☐ Orthop der ☐ Renal y ☐ Senso ☐ Spina y ☐ High F	I Retardation olic/ Endocrirular Dystrophy logical Disordedic Problem (Kidney) Disory Impairmen Bifida	/ ler ns ease it (blind, deaf) ild		
Date of Date of Visit Meas,	Measurements Weight Length	Nutrition Services Provided	Nutrition Diagnosis	Outcome Code		

Children with Special Health Care Needs NUTRITION ASSESSMENT DATA SUMMARY CODES

- 1. Nutrition Assessment
- 2. Reassessment
- 3. Diet Instruction
- 4. Tube Feeding Assessment

Nutrition Services Provided:

- 5. Feeding Assessment
- 6. Nutrition Education
- 7. Diet Check
- 8. Diet Analysis
- 9. Weight Check
- 10. Nutrition Coordination
- 11. Multidisciplinary Conference
- 12. Other

Nutrition Diagnosis:

- Overweight
 Underweight
- 3. Anemia
- 4. Constipation
- 5. Diarrhea
- 6. Feeding difficulties
- 7. Food allergy/ intolerance
- 8. Diet inadequacy
- 9. Drug/ diet interactions
- 10. Slow growth
- 11. Special diet
- 12. Tube feeder
- 13. Alternative diet/products
- 14. Inadequate fluids
- 15. Parent-child feeding interactions
- 16. Gastroesophageal reflux
- 17. Dental disease
- 18. Food insecurity
- 19. No problems
- 20. Other

Clinic Codes

1. < 15 minutes

Length of Visit:

- 2. 26 30 minutes
- 3. 31 60 minutes
- 4. > 60 minutes

- 21 Lewis Co. Public Health
- 32 Spokane Regional Health District
- 42 Spokane Guilds School

Other Clinic

Outcome Codes:

- 1. Problem Identified
- 2. Improved Problem
- 3. No Improvement
- 4. Worse
- 5. Resolved
- 6. Stable

Children with Special Health Care Needs NUTRITION ASSESSMENT DATA SUMMARY

Patient Name:	CSHCN #:	
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Date of Visit	Length of Visit	Date of Meas,	<u>Measu</u> Weight	<u>rements</u> Length	Nutrition Services Provided	Nutrition Diagnosis	Outcome Code

NUTRITION ASSESSMENT DATA SUMMARY:

Outcome Codes Defined Using Specific Examples

 Problem Identified Problem is first identified or reoccurs after being resolved. Use for Nutrition Diagnoses on first visit.

2. Improved Problem:

- Weight gain or weight loss as appropriate
- Improved nutrition intake (diet adequacy) from diet, use of supplements or tube feeding
- Diarrhea or constipation controlled with meds and/or diet
- Timing/ dosages of meds altered to reduce side effects and interactions
- Reflux/ vomiting improved with change of formula, thickened formula or use of meds
- Special diet: compliance improved
- Fluid intake improved
- Tube feeding: problems improved
- Supplement usage altered to acceptable type or amount
- Improved feeding skills or interactions
- Food intolerance: change of diet/formula reduces symptoms
- Gain in length or height

3. No Improvement

- Chronic diarrhea constipation/diarrhea not responding to interventions
- Tube feeding problems unresolved
- Chronic underweight or overweight unchanged
- Feeding difficulties unchanged
- Diet inadequacy unresolved
- Drug/diet interactions unchanged
- Chronic vomiting/reflux unchanged
- Slow Growth: unchanged length or height
- Problem unchanged/ status quo

4. Worse

- Constipation/diarrhea worse
- Tube feeding problem worse
- Loss of weight (underweight)
- Unacceptable gain of weight (overweight)
- Feeding difficulties worse
- Diet inadequacy worse (reduced intake, prescribed supplements not used)
- Vomiting/ reflux worse
- Inadequate fluid intake more severe

Growth in length decreasing in velocity

5. Resolved

- Achieves and maintains weight goal
- Achieves and maintains age appropriate incremental growth
- Linear growth expectations achieved and maintained
- Iron status adequate
- Bowel function normal
- Age-appropriate feeding
- Outgrows food intolerance
- Achieves and maintains adequate nutrition intake
- Drug with potential diet interaction is discontinued
- Feeding tube is removed
- Use of nutrition supplements/ products is appropriate
- Vomiting/ reflux resolved
- Fluid intake adequately maintained
- Parent/ child interactions appropriate
- Special diet no longer prescribed

6. Stable

- Tube feeding is adequate, free from problems
- Drug/diet: medication use continues with diet modified to avoid interactions or recommended supplements are used
- Special diet: compliance is adequately maintained
- Food intolerance: controlled with diet and/ or use of special products
- Linear growth and/or weight is maintained at established growth curve
- Problems such as diarrhea, constipation, reflux/vomiting, feeding difficulties, etc.: problem is not resolved but is treated and controlled with diet, use of medications, dietary texture modifications and so on.

Spokane Regional Health District CSHCN Nutrition 1/7/02