

Nutrition Screening for Infants and Young Children with Special Health Care Needs: Spokane County, Washington

October 2008



Children with Special Health Care Needs Program
Division of Community and Family Health
Washington State Department of Health
PO Box 47880
Olympia, Washington 98504-7880
Publication #970-116



Nutrition Screening for Infants and Young Children with Special Health Care Needs: Spokane County, Washington, October 2008

Written by:

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

Special Acknowledgements to:

MCH Assessment Team
Washington State Department of Health

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

Reviewed by:

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

Maria Nardella, MA, RD, CD
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

This report is posted on the Department of Health Children with Special Health Care Needs Program website in a PDF format. The website URL is:
http://www.doh.wa.gov/cfh/mch/CSHCN_publications.htm

For persons with disabilities, this document is available on request in other formats. To submit a request, please call 1-800-525-0127.

TABLE OF CONTENTS

PURPOSE.....	4
BACKGROUND	4
Nutrition Services in Spokane County	4
Nutrition Screening Program	5
METHODS	5
RESULTS.....	6
Demographics	6
Preterm Birth, Low Birth Weight, and Medical Diagnoses	6
Screening Scores	6
Parental Perspective on Child’s Size and Weight.....	7
Nutritional Concerns Among High Risk Children (5+ Score)	7
Nutrition Services Among High Risk Children (5+ Score).....	9
DISCUSSION AND CONCLUSION.....	9
REFERENCES.....	10
APPENDIX A: A Look at Your Child’s Nutrition	11

PURPOSE

Nutrition services are essential components of comprehensive care for infants and children with developmental disabilities and special health care needs, as described by the American Dietetic Association.¹ Early identification of nutrition risk factors and referral to registered dietitians can play an important role in improving nutritional status and health outcomes for infants and young children with disabilities and special health care needs.

The purpose of this report is to describe the nutrition problems of young children (birth to age three years) entering early intervention programs in Spokane County. This report documents the need for regular nutrition screening of children with special health care needs, both by medical home providers and early intervention programs, and the need for referral networks of registered dietitians for helping children and families get the nutrition services they require. Information provided in this report can be used by policy makers, Interagency Coordinating Council members, early intervention program directors, and health care providers to advocate for including nutrition as a reimbursable service in government and private health plans as well as federal early intervention legislation.

BACKGROUND

Infants and children with special health care needs are at increased risk for nutrition-related problems. Studies point out that between 50 – 90 percent of infants and children with developmental delays or special health care needs have nutritional risk factors that indicate a need for nutrition referral to a registered dietitian.^{2,3,4} Common nutritional concerns include altered growth, i.e., underweight, overweight, short stature, feeding difficulties, nutrient-drug interactions, food intolerances or allergies, constipation, inadequate intake of essential nutrients, and partial or total dependence on enteral or parenteral nutrition.

Nutrition services may be provided in settings such as in the home, child care facilities, hospital, clinic, or early intervention programs. Nutrition and feeding issues of young children are often complex and require a team approach. Registered dietitians frequently work in interdisciplinary teams with physicians, speech therapists, occupational therapists, physical therapists, behavioral therapists, teachers, social workers, and others to meet the needs of the child and family.

Nutrition Services in Spokane County

Young children with developmental delays are eligible to receive early intervention

services authorized by the Individuals with Disabilities Act Part C.[†] Family Resources Coordinators work with families to help them access and coordinate services for their child(ren). As a result of Individuals with Disabilities Act Part C legislation enacted in 1991, registered dietitians have increased their involvement nationally with early intervention programs for young children with developmental delays and their families.⁵ The Children with Special Health Care Needs Program at the Spokane Regional Health District as the Local Lead Agency for Early Intervention Services is responsible for the implementation of Individuals with Disabilities Act Part C in Spokane County.

Nutrition Screening Program

Using a blend of federal, state and local funds, the Spokane Children with Special Health Care Needs Program at the time employed two registered dietitians to provide community-based nutrition services to children, including those enrolled in early intervention services.⁶ These two registered dietitians recognized the need for a nutrition screening program to identify infants and young children with special health care needs who would benefit from early nutrition intervention.

Through work between the Spokane County Interagency Coordinating Council, Family Resources Coordinators, and registered dietitians, a parent-completed nutrition screening form was implemented as a universal nutrition screening for infants and children entering the Infant Toddler Early Intervention Program. The benefit of this screening tool is that it asks parents and caregivers to identify nutritional concerns. In family-centered care, parents are considered the experts in identifying the needs and strengths of their children. The primary purpose of the nutrition screening is to connect children and families with the specialized nutrition services they need.

METHODS

The nutrition screening form used by Spokane Regional Health District, “A Look at Your Child’s Nutrition,” was created by the University of California University Affiliated Program.⁷ Permission was received to modify the form with the local health district logo and list of local programs. The screening form includes questions on demographic characteristics such as age, gender, and race/ethnicity; nutrition and feeding concerns; health conditions, including diagnoses; medications; food security; and services the child is currently receiving. Nutritional risk factors identified in the screening form are assigned points based on severity. Information in the screening form is calculated to create an overall nutritional risk score. (Appendix A)

[†] To be eligible, a child must be under age three and have a 25 percent delay or show a 1.5 standard deviation below his or her age in one or more of the developmental areas. A child may also be eligible if he has a physical or mental condition such as Down syndrome, which is known to cause a delay in development.

Parents, guardians, or caregivers completed the Nutrition Screening Form during the intake visit with the Family Resources Coordinators in Spokane County from April 1, 2004 to March 31, 2007. Family Resources Coordinators assisted parents in completing the forms when requested, and non-English speaking families were provided an interpreter for assistance in completing the form.[‡] Family Resources Coordinators either brought the completed forms back to the office or families had the option to return the forms by mail. As a result of the effort, most of the screening forms were completed and collected. The completed forms were reviewed and scored by the registered dietitians to determine which children were at no, low, or high nutritional risk. Appropriate nutrition referrals were made based on the nutrition screening forms. Table 1 shows the criteria for determining nutritional risk:

Table 1: Nutrition Screening Scores and Nutritional Risk

Nutrition Screening Score	Nutritional Risk
0	No Risk
1 to 4	Low Risk
5 or more	High Risk

After the nutrition screening forms were entered into an Access database, data were exported and tabulated by staff at the Washington State Department of Health.

RESULTS

Demographics

From April 2004 through March 2007, caregivers of 603 infants and young children accessing early intervention services in Spokane County completed nutrition screening forms.

The ages of the children screened were fairly evenly distributed over the first three years of life. Slightly more infants (birth to 12 months) were screened (42 percent) compared to one- and two-year olds. Around three-quarters of the children were Caucasian; 10 percent indicated multi-racial category. Minority groups with 6 percent or less representation included Hispanic, Unknown/Other, American Indian, Asian/Pacific Islander, and Black/African American. Slightly more boys (58 percent) were screened than girls. Although information on socio-economic status was not collected, approximately 8 percent of parents indicated that they did not have adequate resources for buying food for their families.

Preterm Birth, Low Birth Weight, and Medical Diagnoses

One-third of the children screened were born preterm (less than 37 weeks gestational age). Of those who reported their child's birth weight (n = 504), 29 percent had a low birth weight (less than 2,500 grams). Among the low birth weight infants, 42 percent had a very low birth weight (less than 1,500 grams). The majority of the children (52

[‡] The term, "parents", in this document refer to parents, guardians, foster parents, and caregivers.

percent) were identified as having Developmental Delay as a medical diagnosis. Other medical diagnoses that were selected for at least 10 percent of the children were Gastrointestinal Disorder, Other Diagnosis, or Unknown Diagnosis.

Screening Scores

Approximately 72 percent (n = 432) of the children screened had a score of five or more. This indicates that approximately 72 percent of the children screened had a high level of nutritional risk and need for further assessment with possible referral to a registered dietitian. Approximately 26 percent had a score between five and nine, 37 percent had a score between 10 and 19, and 9 percent had a score greater than 20 (Table 2).

Table 2: Nutrition Screening Score, Spokane Nutrition Screening Form, 2004-2007

Score	Number of Children	Percent of Children
<5	171	28
5-9	154	25
10-19	221	37
20+	57	9
Total	603	100

Parental Perspective on Child's Size and Weight

The screening tool asked parents for their perspective on their child's size and weight. Most parents (67 percent) thought their child looked "just right." One-fourth of parents were concerned about underweight status of their child; 6 percent of parents were concerned that their child appeared overweight. Four percent responded that they were concerned about the short stature of their child.

Nutritional Concerns Among High Risk Children (5+ score)

Common nutritional-related concerns included on the screening form are listed in Figure 1. Only 7 percent of the high risk children in this study had just one nutrition issue; approximately half of them had two or three nutritional concerns. The remainder of children (over 40 percent) had four or more nutrition concerns.

Feeding difficulties and food intake problem

Approximately two-thirds of the parents were concerned about feeding issues (Figure 1). These feeding issues include taking a long time to eat (24 percent), choking on liquids (19 percent), difficulty chewing (12 percent) or sucking (11 percent), or eating solids (11 percent). Other feeding concerns indicated possible delays in feeding skill development such as difficulty drinking from a cup (13 percent) or feeding themselves (16 percent), or using a bottle after age two years of age (5 percent). Among children with a score of five or greater (n = 432), approximately 57 percent of parents had concerns about food intake (Figure 1). The most common food intake concerns were about food refusal (28 percent), eating too little (22 percent), or poor appetite (16

percent). Other parents were concerned about their child drinking more than 40 ounces of milk per day (11 percent) or eating too much (5 percent). Some of data mentioned in this section were not shown in the tables or figures.

Use of nutrition supplements and medications

Use of nutrition supplements and products was common in this group of children with special needs. Forty-five percent of parents reported giving their child a vitamin/mineral supplement, herbal product, and/or home remedy. About 43 percent of the children were taking medications prescribed by their physicians.

Gastrointestinal health concerns

Parents were asked to identify whether their child often experienced constipation, diarrhea, and/or vomiting. Around 22 percent of children had chronic constipation while 18 percent were reported to have vomiting or emesis on a regular basis. Parents reported that 15 percent often had diarrhea or frequent, runny stools.

Special diet and food intolerances/ allergies

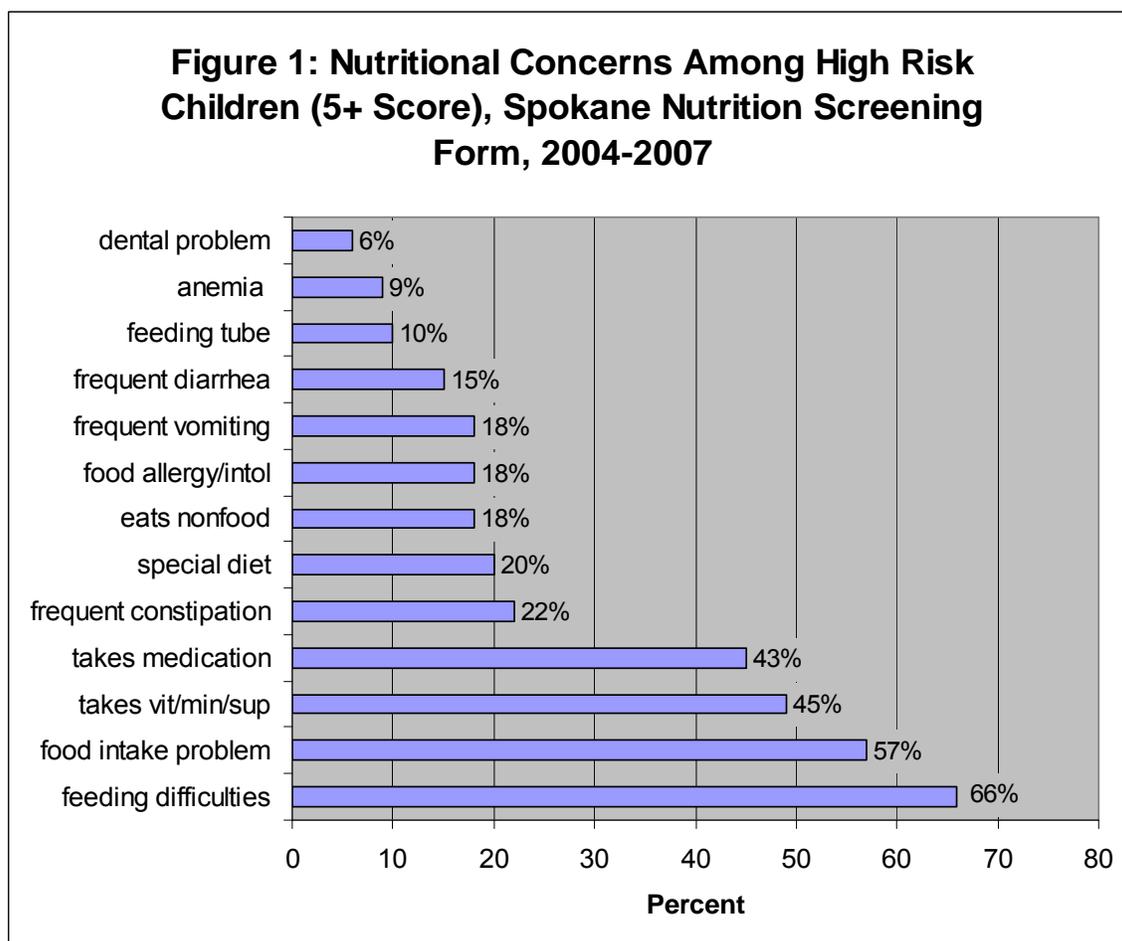
Twenty percent of parents reported that their child required a special diet for a medical condition. Eighteen percent of children were reported to have food allergies or intolerances.

Use of a feeding tube

Ten percent of the children had feeding tubes that provided all or part of their daily nutrition. Children with feeding tubes automatically score in the High Risk category and require assessment and regular monitoring by a registered dietitian.

Other nutritional concerns

Several other nutritional concerns were identified. Eighteen percent of parents were concerned about their child eating nonfood items such as clay, dirt, and starch. Anemia (low blood iron) within the past six months was a nutritional concern with 9 percent of the children. Six percent indicated that their child was currently having dental problems.



Nutrition Services Among High Risk Children (5+ score)

At the time of the screening, approximately 47 percent of children with a score of five or higher were receiving some type of nutrition service. Of this group, over half (61 percent) were receiving nutrition services from the Women, Infants, and Children Program. Other services included home health/enteral supply company registered dietitian (20 percent), feeding clinic (10 percent), and services from a Children with Special Health Care Needs Program registered dietitian (9 percent).

Children with higher screening scores were more likely to be receiving nutrition services. For example, 31 percent of those with a score between five and nine reported receiving nutrition services, 49 percent of those with a score between 10 and 19 received services, as did 84 percent of children who had a score greater than 20.

DISCUSSION AND CONCLUSION

Children with special health care needs have unique nutrition needs and problems. Of the 603 children from birth to three years of age screened between 2004 and 2007 in Spokane County's Early Intervention Program, 432 children (72 percent) were identified

as high risk for nutrition problems. This percentage is similar to that found in other studies.^{2, 3, 4} These children need further assessment with possible referral to a registered dietitian.

While 47 percent of these 432 children were receiving some nutrition service at the time of screening, the majority of children (53 percent) were not receiving any nutrition services. It is also unknown if those who were receiving services at the time of screening were receiving the nutrition services that they needed.

Many of the children entering early intervention have a range of health and developmental conditions. These conditions can add a layer of complexity when providing care to these children for feeding and nutrition problems. Types of feeding problems that may occur in this population include dysphagia (swallowing problems), oral motor feeding problems, sensory feeding issues, developmental feeding delays, and behavioral feeding issues. If feeding problems are not resolved, the child may be at risk for poor weight gain and growth (Failure to Thrive), aspiration pneumonia, and inadequate food intake. Often when feeding issues are addressed, the child's intake of foods also improves.

Gastrointestinal problems, such as constipation, vomiting, and diarrhea in young children with special needs can be chronic and can affect nutritional status. Children who eat nonfood items may be at risk for lead exposure from eating dirt or paint chips. In addition, some medications and herbal products interact with food and nutrients or have side effects that interfere with food intake.

Registered dietitians work closely with children and families to provide assessment, recommendations, education, monitoring and referral. They analyze diets to assure that nutrient needs are met and provide strategies for managing medication and food interactions. Among parents of children with dental problems due to prolonged use of a baby bottle, registered dietitians educate families on preventing caries and work with team members to promote cup drinking skill development. For children who refuse many foods, registered dietitians educate parents about developmental feeding recommendations to help improve their child's food acceptance and intake.

Children who receive tube feedings, for total or supplemental nutrition, require regular assessment and monitoring by a registered dietitian. Registered dietitians can adjust calories and nutrients for growth, assure adequate fluids, make adjustments in tube feeding schedules to meet child and family needs, and help with transition to oral feedings when indicated.

Infants and young children with special health care needs can benefit from early identification and intervention for nutrition problems. A child with special needs who is well-nourished has increased attention span and energy to participate in early intervention therapies and in social and educational activities. Without adequate nutrition, young children may be more susceptible to illnesses and may require increased medical care and hospitalization.

This report supports the need for regular nutrition screening of infants and young children with developmental concerns by medical home providers and early intervention programs. Referral to a registered dietitian is often indicated for assessment and intervention for nutritional concerns. Registered dietitians play an important role in providing assessment, recommendations, education, monitoring and referral for infants and young children with feeding and nutrition problems and their families.

REFERENCE

1. Position of the American Dietetic Association: Providing nutrition services for infants, children, and adults with developmental disabilities and special health care needs. *J Am Diet Assoc*, 104:97-107, 2004. <http://www.eatright.org>
2. Lichenwaller, L. et al. Providing nutrition services to children with special needs in a community setting. *Top Clin Nutr*, 8:75-78, 1993.
3. Ekvall S, Ekvall V. Early Intervention and Nutrition. In Stevens F, Ekvall S, eds. *Empowering Children Through Early Intervention with Good Nutrition. Manual IV*, MCHB. Rockville, MD HRSA; 7 – 20, 2001.
4. Whittington, S. Nutrition services in an early intervention program by a registered dietitian employed by the program. *PNPG Post*, 16:2, Winter, 2006.
5. Cloud, HH. Nutrition services for children with disabilities and special health care needs. *Top Clin Nutr*, 16:28-40, 2001.
6. Gilliam, J, Laney S and Yang, Y. Community based nutrition services for children with special health care needs in Spokane County. 2006. Available at: http://www.doh.wa.gov/cfh/mch/CSHCN_publications.htm
7. Nutrition screening and referral in *Nutrition Strategies for Children with Special Health Care Needs*. UAP Center for Child Development and Developmental Disabilities, Children's Hospital Los Angeles, 1999.



Appendix A: A Look at Your Child's Nutrition

A Look at Your Child's Nutrition

Nutrition Screening Form

Office Use Only ID# _____
Location _____
FRC _____

Today's Date: _____
Child's Name: _____ Age: _____ Birth date: _____ male female
Your Name: _____ Phone #: _____ Relationship to child:: _____
Address: _____ City: _____ State: _____ Zip: _____

Birth weight: _____
Was your child premature (born early)? yes no (2 pts if < 2 y.o. and LBW or PM) If yes, how many weeks early? _____
Was your child breastfed? yes no If yes, for how long? _____

The following questions will help us learn more about your child. Please answer each of the following questions.

1. How does your child appear to you?
 overweight (3) underweight (4) just right short (2)
If available, what is your child's most recent: weight _____ height _____ date of measurement: _____
2. Do any of the following apply to your child's food intake? yes (3) no
If yes, check all that apply.
 refuses many foods drinks more than 40oz. milk per day (5 cups) eats too much
 refuses solid foods has poor appetite eats too little
 eats fewer than 3 times per day other: _____
3. Does your child have any feeding or eating problems? yes (4) no
If yes, check all that apply.
 difficulty sucking difficulty feeding self chokes on solids
 difficulty chewing foods chokes on liquids loses food from mouth
 using bottle after age 2 years difficulty drinking from a cup takes a long time to eat
 other: _____
4. Does your child have a feeding tube? yes (5) no
5. Is your child on a special diet for a medical condition (e.g., diabetes, PKU,...)? yes (4) no
If yes, what kind? _____
6. Is your child allergic to, or intolerant of, any foods? yes (2) no
If yes, what foods? _____
7. Does your child often have diarrhea? yes (3) no
8. Does your child often have constipation? yes (2) no

Appendix A: A Look at Your Child's Nutrition

9. Does your child often vomit? yes (3) no
10. In the past six months was your child found to be anemic (low blood iron)? yes (2) no
11. Does your child currently have dental problems?..... yes (1) no
12. Does your child take medications? yes (2) no
 If yes, what medications and for how long? _____
-
13. Does your child take vitamins/minerals/home remedies/herbal products?..... yes (1) no
 If yes, name of supplement(s)? _____
14. Does your child eat any non-food items (clay, dirt, starch,...)..... yes (4) no
 If yes, specify: _____
15. What is your child's activity level?
 walks independently needs help walking (braces/walker) (2)
 does not walk not old enough to walk
16. Do you have trouble buying enough food to feed your family? yes (3) no
17. Does your child participate in any of the following programs? Check all that apply.
 WIC SSI Foster Care DDD
 ITN/CSHCN Medicaid School District Home Health
 Early Intervention Provider Private Insurance Head Start/Early Head Start Feeding Clinic
 Public Health Nurse Food Stamps Other: _____
18. Do you have any additional concerns about your child's growth, nutrition or eating? ... yes (1) no
 If yes, what are your concerns? _____
19. Is your child currently receiving nutrition services? yes no
 If yes, name of person or agency: _____

Child's Ethnicity (check major one):

- Caucasian Hispanic/Latino American Indian African American Asian/Pacific Islander Other/Unknown Multi-Racial

Child's Medical Diagnosis (check any which apply):

- Asthma/Pulmonary Disease Autism Spectrum Disorder Bronchopulmonary Disease (BPD) Cancer
Congenital heart disease Cerebral Palsy Chromosome disorder (i.e., Down Synd.) Cleft lip/palate
Cystic Fibrosis Developmental delay Epilepsy/seizures Gastrointestinal disorder
Metabolic/endocrine disorders Muscular Dystrophy Neurological disorder Orthopedic problems
Renal (kidney) disease Sensory impairment (blind, deaf) Spina Bifida Unknown diagnosis
Other:

