COST CONSIDERATIONS:

The Benefits Of Nutrition Services For A Case Series Of Children With Special Health Care Needs In Washington State

May, 1998



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DOH Publication Number 970-212

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Supported in part by Project MCJ-537063 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services

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ACKNOWLEDGMENTS

Thanks to Maria Nardella, MA, RD, Nutrition Consultant with the Office of Children with Special Health Care Needs, for her initiation of this project and ongoing support throughout the process.

We appreciate the thoughtful review of this document by Cathy Wasserman, PhD, Epidemiologist and Manager of the Maternal and Child Health Assessment Section within the Washington State Department of Health.

This document would not be possible without the contributions from nutritionists and feeding teams from Washington State. Thanks to the following nutritionists and feeding teams who provided case studies:

Diane Armbrust, MS, RD, CD Christine Avgeris, MS, RD Kathy Canny, RD, CD Cheryl Polasek, RD, CD Becky Esvelt, RD, CD Kari Fisher, MS, RD, CD Annie Frederick, RD, CD Jan Gilliam, RD, CD Sandi Laney, RD, CD Jody Martin, RD, CD Kathleen Paganelli, RD, CD Kristine Schmidt, RD, CD Carolyn Schuck, RD, CD Lewis County Children's Hospital & Medical Center, Seattle Thurston County Cowlitz County Ferry, Stevens, and Pend Oreille Counties King County Home health agency, Spokane County Spokane County Spokane County Spokane County Kittitas County Yakima County Lewis County Walla Walla County

Cowlitz-Wahkiakum Feeding Clinic Benton Franklin Feeding Team Eastside (King County) Feeding Team Southwest Washington Feeding Team Lewis County Interdisciplinary Feeding Team Thurston County Interagency Feeding Team Spokane County Home-Based Feeding Team PKU Clinic, CHDD, University of Washington

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The Benefits of Nutrition Services for a Case Series of Children with Special Health Care Needs in Washington State

ABSTRACT

A case series of 30 children with a wide variety of special health care needs and nutrition-related problems was collected by registered dietitians and community feeding teams in Washington State between 1993 and 1996. The children ranged in age from 11 days to 17 years, and had multiple visits over variable time periods within a variety of settings. The estimated medical costs avoided exceeded the intervention costs for nutrition and feeding team services for 28 of the 30 children. The ratio of intervention costs to medical costs avoided ranged from 1:0.8 to 1:20. The report demonstrates that an investment in professional time with multiple family/child contacts can achieve improvements in nutrition and feeding problems and result in savings in overall health care expenditures.

The Benefits of Nutrition Services for a Case Series of Children with Special Health Care Needs in Washington State

EXECUTIVE SUMMARY

Children with special health care needs are at increased risk for a variety of nutrition and feeding problems, including altered growth, medical conditions that increase energy and nutrient needs, delayed or impaired oral motor skills, inappropriate or inadequate food intake, need for specialized feedings, and feeding behaviors that limit an adequate diet. These children and their families are also at risk for inadequate nutrition and feeding information. Many of the complex nutrition and feeding problems of children with special health care needs require the expertise of more than one health care discipline. Interdisciplinary teams have been shown to be effective for assessing and providing appropriate, coordinated intervention for these challenging situations, while reducing appointments for the family and avoiding conflicting or contradictory advice. Despite the benefits anecdotally described by health care professionals and families of these children, cost effectiveness data on nutrition and feeding team services for children with special needs has not been documented.

In order to demonstrate the costs and benefits of nutrition and feeding team services for children with special health care needs without doing a full scale study of cost effectiveness, a case series of 30 children were collected by registered dietitians (RDs) and community feeding teams in Washington State between 1993 and 1996. The children received services in community, out-patient or home settings, and they reflect a variety of medical conditions and congenital or genetic disorders. These case studies were not randomly selected, there was no comparison control population and the specific cases do not necessarily represent all children with similar diagnoses. Costs for the interventions provided and the interventions avoided were based on actual reported costs of providing these services in the community, or the costs were assigned uniformly, based on common practice in Washington State.

The children were 11 days to 17 years of age, and had multiple visits (four to 23 visits) over a period of time, typically from six to 24 months. The most common primary medical diagnoses for these children included cerebral palsy, cardiac disease, developmental delay and complications secondary to prematurity. Most of the children presented with three or more nutrition-related problems. The majority of the nutrition and feeding problems were poor growth, inadequate or inappropriate dietary intake, and oral motor feeding problems.

Positive outcomes for these children following nutrition or feeding team interventions included: appropriate growth, improved dietary intake and adequacy, decreased illness and hospitalization, improved feeding skills and feeding behavior, and progress in feeding development. The greatest improvements were in growth and

dietary intake which addressed the frequent initial problems of poor growth and inadequate diet.

The range of intervention costs in the 20 RD/nutritionist case studies was \$120 to \$6075, and the range of estimated medical costs avoided was \$300 to \$15,860. The estimated costs savings ranged from \$180 over a one year period to \$9980 over a two-year period of intervention in 19 of the 20 case studies. The range of intervention costs for nine feeding team case studies was \$550 to \$17,760, and the range of estimated medical costs avoided was \$2400 to \$14,485. The estimated costs savings ranged from \$1700 over a four month period to \$8100 over one year in eight of the nine case studies. For two children (one RD/nutritionist case and one feeding team case), the intervention costs exceeded the costs of the interventions avoided by 19% and 23%. For these two children and some of the others described, additional savings could be anticipated in the future, especially if they remain healthy and/or receive regular nutrition screening to avoid a recurrence or worsening of the nutrition and feeding problems.

For these 30 case studies of children in Washington State, the estimated medical costs avoided exceeded the intervention costs for 28 children. The ratios of intervention costs to medical costs avoided ranged from 1:0.8 to 1:20. The case studies demonstrate the benefits of providing nutrition and feeding team services for a selected group of children with special health care needs in a wide range of settings. They show how an investment in professional time with multiple family/child contacts can achieve improvements and resolution of nutrition and feeding problems and result in savings in overall health care expenditures. Once a nutrition or feeding problem is either resolved, well managed, or caught early, the costs of periodic monitoring and re-assessment are likely to be low compared to the costs of medical and nutritional intervention in crises or severe situations.

Preventing and addressing nutrition concerns depends on the availability of nutrition screening as a part of primary and specialty pediatric care to identify children needing early nutrition intervention. While the cost of incorporating routine pediatric nutrition screening into clinical practice needs to be further evaluated, the findings from this report suggest that the costs of early identification and treatment are likely be low in comparison to potential savings. Many of the children described in this document received early, periodic nutrition screening and intervention. Medical and treatment costs are likely to have been greater if the nutrition screening and subsequent intervention had been delayed or had not been provided.

While further studies are needed to document the cost effectiveness of nutrition and feeding team services for children with special health care needs, this report supports the following recommendation to contribute to a reduction in overall health care expenditures:

Nutrition and feeding problems should be identified early and referred for assessment and intervention by qualified nutrition and other health care professionals who have experience and training in working with children with special health care needs and their families.

INTRODUCTION

Children with special health care needs are defined as children who have ongoing health conditions that:

- have a biological, psychological, or cognitive basis
- have lasted or are virtually certain to last for at least one year
- produce one or more of the following sequelae: limitation of function, activities or social role in comparison with healthy age peers in the general area of physical, cognitive, emotional, and social growth and development
- depend on one of the following to compensate for or minimize limitation of function, activities, or social role: medications, special diet, medical technology, assistive device, personal assistance
- need medical care or related services, psychological services or educational services over and above the usual for the child's age, or special ongoing treatments, intervention or accommodations at home or in school (1).

According to a 1997 report, approximately 18% of children in Washington State in 1993 had some type of chronic condition, such as respiratory disorders, musculoskeletal disorders and attention deficit disorder, with about 1% having severe conditions (2). Many of these children require more than the usual pediatric health care. Some need only periodic health screening and monitoring; others require specialty or subspecialty care.

Nationally, as many as 40% of children with special health care needs have been estimated to be at risk for nutrition problems; with certain conditions and diagnoses, the rate is even higher (3). The higher incidence of nutrition and feeding problems are due to a variety of factors. These include:

- conditions or syndromes that alter growth and development, and change nutrient needs
- alterations in digestion, absorption, metabolism, and excretion related to inherited or acquired disorders, surgery or medications
- delayed or impaired oral motor skills needed for sucking, swallowing, eating and drinking
- delayed fine and gross motor abilities needed for self feeding
- cognitive impairments and/or behavioral disorders that result in inappropriate food intake or feeding practices
- limited financial resources or inadequate nutrition and feeding information for caregivers
- need for specialized feeding equipment, enteral or parenteral feeding, or special medical foods

Most nutrition and feeding problems of children with special needs can be improved or controlled, but often are not totally resolved. Therefore, these children will require ongoing and periodic nutrition assessment and intervention. The frequency and intensity of nutrition services will depend on the child's medical condition, rate of growth and development, and secondary complications. For many children, frequent nutrition intervention and monitoring are needed in the early months and years of life, followed by less frequent, but regular, assessment and monitoring as their conditions and overall health become stable with age.

Preventive nutrition services for this population, which include early identification and treatment, can help alleviate malnutrition, growth retardation, frequent infections, dehydration, and other medical consequences (4). Preventing nutrition and feeding problems may also decrease the need for physician visits and hospitalizations. For the family, a well-nourished child with special health needs means fewer days of absence from school and work, greater ability to participate in therapy and educational programs, and better overall functioning in everyday life. See letters of support for nutrition services from parents and professionals in Appendix A.

Early identification and screening for nutrition concerns is typically done by the primary care provider or other health professional. If needed, this is followed by appropriate referral for a nutrition assessment and intervention by a qualified nutrition professional, a registered dietitian (RD). If no concerns are identified by the screening, the child is re-screened periodically. This coordinated system of nutrition care helps enable the child to be as healthy and independent as possible.

Many of the nutrition and feeding problems of children with special health care needs are complex and multi-factorial, requiring the expertise of more than one health care discipline. Interdisciplinary teams have been shown to be effective for assessing and providing appropriate, coordinated interventions for these challenging situations. An interdisciplinary feeding team can draw members from the following disciplines: nutrition, occupational therapy, speech therapy, nursing, physical therapy, social work, education specialist, and primary care provider. A team approach to feeding problems of these children can:

- reduce the number of appointments for a family because nutrition and feeding can be addressed by the team concurrently
- avoid the delivery of conflicting or contradictory nutrition-related advice to families
- help families and team prioritize the problems and intervention strategies

EFFECTIVE OUTCOMES OF NUTRITION SERVICES

Diet and nutrition are contributing factors to the overall health of all Americans, not just children with special needs. Eight of the 10 leading causes of death, including coronary heart disease, some types of cancer, diabetes mellitis, and stroke, are related to diet and alcohol (5). In 1992, diet-related diseases and conditions used a substantial portion of the \$819.9 billion of the country's health care costs (6).

According to the U. S. Preventive Services Task Force, screening for nutrition risks and problems is defined as an expected part of routine preventive health services (7). Screening, assessment, and appropriate intervention in preventive health care has economic benefits—individuals stay healthy and have reduced incidence and severity of chronic diseases, reduced medical costs for medications, surgery, hospitalization and extended care, and improved quality of life.

Medical nutrition therapy (MNT) refers to the comprehensive nutrition assessment of an individual, followed by appropriate interventions to achieve desired health outcomes. These interventions include diet modifications and counseling or specialized nutrition therapies such as enteral/parenteral feedings or special medical food supplements. MNT saves money by providing alternatives to more costly therapies, decreasing hospital stays, and preventing the need for hospitalizations and surgeries (8).

Reports have demonstrated the cost benefits of MNT in various conditions, such as diabetes mellitis (insulin-dependent and non-insulin-dependent), hypercholesterolemia, and hypertension (8). In prenatal care, for every dollar invested in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) for pregnant women, there is up to \$4.21 saved in Medicaid expenses for the complications of low birthweight infants (9).

Although a 1993 review of the literature found 120 articles on clinical effectiveness of dietetic services, no articles included children and adolescents (10). In particular, cost effectiveness data for children with special needs has not been documented, despite the benefits anecdotally described by health care professionals and families of these children. In 1995, Dietetics in Developmental and Psychiatric Disorders, a dietetic practice group of the American Dietetic Association, published a report of case studies that included children with special health care needs, but a cost-benefit design was not used (11).

PURPOSE

The development of this document is the result of a collaborative effort between the Center on Human Development and Disability, University of Washington, and the Office of Children with Special Health Care Needs, Washington State Department of Health. The goal was to document the costs and benefits of nutrition services for selected children with special health care needs, provided by RDs, in community or ambulatory settings. There was also interest in considering the costs and benefits of feeding team services for feeding and nutrition problems in this population. Results of this effort were expected to begin the process of documenting costs and subsequent outcomes of services. Another objective was to increase the awareness of the kind and extent of services needed to obtain resolution of nutrition and feeding problems in this population.

METHODS

This document includes a case series of 30 children with special health care needs from Washington State who received nutrition or feeding team services. All of these children received their services in a community, out-patient or home setting.

The information was collected and documented by a group of RDs (CSHCN Nutrition Network) in Washington State who have received training to provide nutrition services for children with special health care needs. Additional case studies were submitted by community feeding teams which include some of these RDs and other health care professionals as members. Community-based feeding teams have been trained in Washington since 1993, and guidelines were published for the development and training of these teams (12). A standardized case study form was used to collect the information. See Appendix B for sample forms.

The CSHCN Nutrition Network dietitians are employed in a variety of settings across the state of Washington including:

- WIC Programs
- Local Health Departments/Districts
- Children with Special Health Care Needs (CSHCN) programs in local health departments
- Early Intervention (Birth to Three) Programs
- Hospitals
- Home Health Agencies

The children described in these case studies reflect a variety of medical conditions and congenital or genetic disorders which can be seen in a population of children with special health care needs. These were conditions or disorders that required nutrition or feeding team interventions. A total of 43 case studies were originally submitted by the participating RDs and feeding teams who selected children from their caseloads with whom they had had multiple encounters and access to the data needed to complete the cost analyses. Only 30 case studies are presented in this document. Those not included were duplicative of similar conditions or lacked sufficient detail to determine the costs, but were otherwise not different from those included here. There is representation from the metropolitan areas of Seattle and Spokane, smaller cities and rural communities in Washington State (See map in Appendix C).

The children described in this case series range in age from 11 days to 17 years (Fig. 1). The data were collected between 1993 and 1996, although some interventions may have been initiated earlier and/or extended beyond this time period. A majority of the children had multiple visits (range of four to 23 visits) over a period of time, typically from six to 24 months. However, the frequency of visits depended on the child's condition and status, i.e. some were weekly during a critical period and others were monthly or quarterly.



LIMITATIONS OF THIS DOCUMENT

The collection of these case studies by community nutritionists and feeding teams was done without additional support or compensation to those individuals. Since this is a case series, inferences cannot be drawn from these data to the entire population of children with special health care needs. The following limitations should be considered in using and interpreting these data:

- the case studies were not randomly selected and do not represent the entire population of children with special health care needs
- the nutritionists and feeding teams were not randomly assigned to provide interventions
- the case studies represent the more successful outcomes of the RDs and feeding teams interventions
- marginal or unsuccessful interventions probably exist but are not represented here
- the case studies were included with regard to the presenting nutrition and growth concerns, not the type or severity of disability
- costs incurred for interventions (or costs saved) were dependent on that child's specific condition, severity, and nutrition care, and do not necessarily represent all children with similar diagnoses or care
- other intervening variables may have influenced some of the outcomes
- costs avoided were based on clinical judgment, not on a comparison with a control population

COSTS OF PERSONNEL

The costs of personnel vary from case to case in this document. Variations are due to:

- the setting through which the nutrition and feeding team services took place, i.e. hospital, community primary care clinics, programs such as WIC or early intervention education programs
- the experience of the RD/nutritionist and feeding teams
- the length and frequency of the contact time
- the funding source(s) of the nutritionist or feeding team members, i.e. WIC, Medicaid reimbursement, federal block grant salary support, fee for service

Personnel costs were based on the actual salary, benefits and overhead reported by the RDs and feeding team members. Since many of these providers were employed in local health departments in non-urban areas, those costs may be lower than in other health care delivery settings. If unreported by providers, costs for RD services were uniformly estimated by project staff, based on a selected typical salary plus a percentage applied for benefits/overhead (\$30 per hour). RDs in private practice would be likely to charge two to three times that amount.

OTHER HEALTH CARE COSTS

Costs of special formulas and feeding equipment were included if they were part of the intervention or costs avoided. These costs were calculated based on an average between reimbursable state rates, home health agency rates and retail rates. Formula costs were not included if the product, such as standard infant formula, was the developmentally usual source of nourishment.

The actual costs for hospitalization, physician visits, and procedures were used in those case studies that reported them. When this information was not reported, estimated costs avoided were based on generally accepted values in Washington State in 1995-96, using conservative estimates. These cost estimates were obtained from hospitals, home health agencies, pharmacies, and providers. Actual costs are difficult to document because there is some variation across the state based on location and personnel costs. The following values for typical procedures or evaluations were used in this document for comparative purposes:

\$2400 for hospital evaluation of failure to thrive

\$5700 for placement of a gastrostomy feeding tube

- \$100 per primary care provider (PCP) visit with prescribed medications
- \$550 per day for hospitalization (basic care room rate)

Amounts for services were rounded to the nearest dollar or ten dollars, if appropriate. The families' out-of-pocket expenses, i.e. travel, child care, absences from work, as well as intangible impacts, were not included or addressed in either the intervention costs or the cost savings.

RESULTS

The 30 case studies of children with special health care needs are on pages 21-54. There are 20 from RD/nutritionists and 10 from feeding teams. Although the term "nutritionist" is used in most of the case studies, this reflects a job title. In fact, all of the nutritionists are RDs and also certified dietitians (CD) in Washington State. The same format is used for all case studies. The *interventions* are the actual contacts by the nutritionists or feeding teams, and the primary treatment or recommendations. *Outcomes* are the results or changes in status after the interventions. *Interventions avoided* are actual or anticipated (based on previous history) procedures, hospitalizations, medical appointments, and related supplies that were avoided, plus their costs. *Intervention costs* are the actual and estimated costs of providing the nutritionist or feeding team services, including frequency and length of time.

RD/NUTRITIONIST CASE STUDIES

There were a variety of nutrition and feeding problems described in the 20 case studies contributed by nutritionists (Fig. 2). Most of the problems, however, centered on poor growth and inadequate or inappropriate dietary intake. Fifteen of the 20 children (75%) presented with three or more nutrition-related problems.





 \ast Many children presented with more than one problem.

The most frequent primary medical diagnosis was cerebral palsy for six of the 20 children (30%) (Fig. 3). Cardiac disease and developmental delay (unspecified) were the next most frequent diagnoses.

Figure 3. **RD/NUTRITIONIST CASE STUDIES** Primary Diagnosis of 20 Children Cerebral Palsy Cardiac Disease Developmental Delay (unspecified) Arthrogryposis Down Syndrome Failure to thrive Megaesophagus/tracheomalacia Metabolic/Endocrine Partial trisomy 16q-Russel Silver syndrome 14 10 12 18 2 4 8 16 20

The positive outcomes for these 20 children following nutrition intervention included:

- Appropriate growth in all of the children who had slow growth or failure-tothrive
- Improved dietary intake and adequacy in all of the children who had inappropriate or inadequate intake
- Decreased illness and hospitalization
- Improved feeding skills
- Improved feeding behavior
- Decreased constipation
- Developmental feeding progress

The greatest improvements were in growth and dietary intake which addressed the frequent initial problems of poor growth and inadequate diet.

FEEDING TEAM CASE STUDIES

Inappropriate or inadequate intake and oral motor feeding problems were the main problems presented in the 10 feeding team children (Fig. 4). This reflects the complex nature of children whose feeding difficulties impact adequate nutrition and growth, which in turn negatively affects their health and perpetuates the feeding problems. With some children this results in a downward cycle, further complicated by poor feeding interactions and behaviors. Many of the children in these cases also had multiple nutrition and feeding problems by the time they were referred to the feeding team.





* Many children presented with more than one problem.

The primary medical diagnosis of the feeding team case studies was unspecified developmental delay in five of the 10 children, followed by cardiac disease and complications due to prematurity (Fig. 5). The unspecified developmental delays likely reflect the fact that all of these children were less than five years old. Specific diagnoses at these young ages are frequently less definitive.





* Includes 2 children with dual diagnoses

The most frequent positive outcomes of the 10 feeding team case studies were similar to the RD intervention case studies, and included:

- Improved dietary intake and adequacy in all nine of the children who had dietary inadequacy
- Appropriate growth in six of the children
- Improved feeding skills in five of the children
- Decreased illness and hospitalization in four of the children
- Developmental feeding progress
- Improved feeding behavior

COST SAVINGS

RD/NUTRITIONIST CASE STUDIES

Figure 6 includes the costs of nutrition interventions and the estimated medical costs avoided in conjunction with, or as a result of, the nutrition services provided in the 20 RD/nutritionist case studies. The range of intervention costs was \$120 to \$6075, and the range of estimated medical costs avoided was \$300 to \$15,860. The estimated costs savings ranged from \$180 over a one year period to \$9980 over a two-year period of intervention in 19 of the 20 case studies. In one case study (Case 19), the intervention costs exceeded the costs of the interventions avoided by \$975, or 19%. This was due in part to the cost of placing a G-tube for delivering medications, but which had the additional result of improving the child's hydration status. Future savings for medical costs of treating dehydration could be anticipated.



For these children, the estimated medical costs avoided exceeded the nutrition intervention costs in 19 of the 20 case studies. The ratios ranged from 1:0.8 to 1:20. The case studies demonstrate the potential benefits of providing nutrition services to a select group of children with special health care needs.

FEEDING TEAM CASE STUDIES

With the feeding team case studies, one case study included anticipated costs savings beyond the time frame of other cases in this document, i.e. extending into adulthood. Because of its atypical nature, this case study (Team Case # 10) was excluded in the cost comparisons, and the remaining nine were used.

Figure 7 shows the costs of the feeding team interventions and the estimated medical costs avoided. The range of intervention costs was \$550 to \$17,760, and the range of estimated medical costs avoided was \$2400 to \$14,485. The estimated costs savings ranged from \$1700 over a four month period to \$8100 over one year in eight of the nine case studies. For one child (Team Case #9), the intervention costs exceeded the costs of the interventions avoided by \$3275, or 23%. This child had complicated medical conditions which impacted nutritional status and delayed feeding development. To address these complex issues, the feeding team worked with an expanded health care/community resource team, which increased the personnel costs for the interventions. However, these efforts facilitated coordinated and timely interventions which likely reduced medical costs beyond this reporting period.



For these children, the estimated medical costs avoided exceeded the costs of feeding team interventions in eight of the nine case studies. The ratios ranged from 1:0.8 to 1:7.4. The case studies demonstrate the potential benefits of providing feeding team services to a select group of children with special health care needs.

DISCUSSION

These 30 case studies of children in Washington State document the benefits of providing nutrition and feeding team services for a select group of children with special health care needs in a wide range of settings. For 27 of the children, the estimated medical costs savings after the provision of RD or feeding team services ranged from \$180 over a one year period to \$9980 over a two-year period. For two children, one RD case study and one feeding team case study, the intervention costs exceeded the estimated medical costs by 19-23% during the intervention period. For these two children and some of the others described here, additional savings could be anticipated in the future, especially if they remain healthy and/or receive regular nutrition screening to avoid a recurrence or worsening of the nutrition and feeding problems.

Nutritional status, growth, feeding skills, and feeding behaviors improve and change over time. Progress can seem slow for families with children who have special health care needs, especially for those children with developmental delays. These case studies show how a significant investment in professional time with multiple family/child contacts can achieve improvements and resolution of nutrition and feeding problems and result in savings in overall health care expenditures.

The cost benefit potential of nutrition and feeding team services can be realized for providers, families, and payers of medical care who employ these services. Due to their diagnosis or condition, many children with special needs require ongoing periodic nutrition assessment and intervention, and there are concerns about the continual costs of these services. However, once a nutrition or feeding problem is either resolved, well managed, or caught early, the ongoing costs of periodic monitoring and re-assessment are likely to be low compared to the costs of medical and nutritional intervention in crises or severe situations.

Well-designed studies of effectiveness, cost-effectiveness, and cost benefits require a comparison of the costs and outcomes of two or more alternative interventions (13). This kind of analysis has not been a priority in health service delivery models in the past. Evaluating nutrition effectiveness has also been a challenge because nutrition intervention is often a part of other services such as prenatal care or ongoing management of chronic conditions. To ensure the ongoing availability of nutrition services with the transition to managed care and cost containment, regular documentation and evaluation of nutrition services for children with special needs is in order.

A key element in preventing and addressing nutrition concerns in this population of children is the availability of nutrition screening as a part of primary and specialty pediatric care. With a nutrition screening tool and appropriate training, nutrition screening is usually performed by nurses or other health professionals in conjunction with the delivery of other services, but can also be done by a variety of clinic and program staff, educators, and family members. The cost of incorporating routine pediatric nutrition screening into clinical practice needs to be further evaluated and the cost of screening needs to be considered in determining cost benefits of nutrition services for these children. No studies of this nature have been reported to date.

The findings from this report suggest that the cost benefits of early identification and treatment are likely be low in comparison to potential savings. Many of the children described in this document received early, periodic nutrition screening and intervention. Medical and treatment costs may have been greater if the nutrition screening and subsequent intervention had been delayed or had not been provided. Providers and health care plans that incorporate nutrition screening as a part of standard pediatric practice, followed by appropriate referral, as needed, for nutrition assessment and intervention by a trained RD/nutritionist or feeding team, could benefit from savings in overall health care expenditures.

Families, too, will benefit if their children receive regular nutrition screening and access to intervention for nutrition and feeding problems. (See letters from parents in Appendix A). This was documented in a 1994 report of focus groups on nutrition for parents of children with special health care needs in Washington State (14). One of the primary findings of the parent focus groups was that nutrition interventions for their children were initiated as a reaction to a chronic problem that culminated in a crisis, such as severe weight loss, extreme feeding difficulties, aspirations and the placement of a feeding tube. Overwhelmingly, these parents felt that earlier nutritional intervention would have been beneficial for their children. For families, therefore, some benefits are significant, but perhaps less quantifiable - healthier children who grow and develop to their full potential; parents who are satisfied with the comprehensive health care their children receive; and less stress and anxiety related to illness, negative feeding interactions, and frequent medical appointments.

RECOMMENDATIONS

While further studies are needed to document the cost effectiveness of nutrition and feeding team services for children with special health care needs, this report supports the following recommendation to contribute to a reduction in overall health care expenditures:

Nutrition and feeding problems should be identified early and referred for assessment and intervention by qualified nutrition and other health care professionals who have experience and training in working with children with special health care needs and their families.

Although not resulting from the foregoing cost analyses, the following recommendations are supported by experts in nutrition for children with special health care needs to promote optimal and more effective nutritional care. Additional well-designed studies are needed to document specific costs and benefits.

- 1. Families, health care providers, and coordinators in managed care plans need to know how to access qualified nutrition and feeding professionals who work with children with special health care needs.
- 2. There should be flexibility in health care coverage and benefit packages to accommodate those children who need more intense, frequent professional contacts to resolve or mediate their nutrition and feeding problems.
- 3. All children with special health care needs should receive early and regular screening for nutrition problems by primary care providers or other health care professionals.
- 4. Training related to nutrition screening and referral for nutrition and feeding problems in these children should be provided to primary care providers and other non-nutritionist health care providers.
- 5. Regular preventive nutrition education and services should be provided to families of children with special health care needs to decrease the incidence and severity of nutrition problems, and to monitor risk factors for developing these problems.
- 6. Nutritionists and feeding team providers should provide outcome-based interventions to be able to document the cost benefits and cost effectiveness of these services to children with special health care needs.
- 7. Health care providers and plans should include family satisfaction in assessing the quality of care and the inclusion of nutrition services provided to this population.

GLOSSARY FOR CASE STUDIES

- BPD bronchopulmonary dysplasia
- CD Certified Dietitian, meets criteria recognized by the Washington State Department of Health, Division of Licensing
- CDS Communication Disorders Specialist
- DD Developmental delay
- FRC Family Resource Coordinator
- FTT Failure to thrive
- G-tube Gastrostomy feeding tube
- NG Nasogastric
- **OT** Occupational Therapist
- PCP- Primary Care Provider
- PDA Patent Ductus Arteriosus
- PHN Public Health Nurse
- PT Physical Therapist
- RD Registered Dietitian of the American Dietetic Association
- **RN Registered Nurse**
- SLP Speech and Language Pathologist
- URIs Upper respiratory infections
- WIC Special Supplemental Nutrition Program for Women, Infants and Children
- wt/age weight for age
- wt/ht weight for height
- %ile percentile

RD/NUTRITIONIST CASE STUDIES

- SITE: County Health Department
- CLIENT: 5 year old female
- DIAGNOSIS OR CONDITION: Severe static encephalopathy, spastic quadriplegia, complex seizure disorder, global developmental delay, cortical blindness and status post Nissen fundoplication with G-tube secondary to aspiration risk, scoliosis. History of obesity, erratic weight status, drug/nutrient interactions, repeat URIs, poor feeding tolerance, femur fracture x2, and constipation. Poor parental bonding after placement of feeding tube at 9 months of age.
- INTERVENTION: Quarterly home visits by RD to monitor growth and assess/adjust G-tube feeding beginning at age 3 years. RD initiated consultation with pediatric hospital and speech therapist regarding oral feeds for social stimulation and improved parental bonding. Switched to continuous drip feeding to improve feeding tolerance. Visits: 4 per year for 2 years.
- OUTCOMES: Erratic growth pattern has stabilized. One hospital day in 2 years since intervention versus 16 hospital days in 2 years prior to RD contact. One PCP visit for illness in 2 years of contact with RD versus 7 PCP visits for illness in two years prior to RD contact. Use of high calorie pediatric nutrition liquid supplement with fiber, and initiating proper medication resolved the constipation. Support helped parents with their fragile child. Consistent visits facilitated a relationship of mutual trust between parents and RD, and improved the quality of life for the family.
- INTERVENTIONS AVOIDED: Total = \$8620 (Over two years fewer PCP visits, fewer antibiotics, fewer hospital days, PCP \$60/visit/4 visits-\$240, 10 hospital days-\$5500, formula and supplements-\$2880/2 years. Saved possible medical care for caregiver back problems, and foster care if parents "burn out").
- INTERVENTIONTotal = \$3880 (Formula and supplements-\$2880/2 years.COSTS:Personnel (RD) \$1000/2 years).

COST SAVINGS OF Saved \$4740 over two years.

INTERVENTION:

SITE:	County Health Department
CLIENT:	4 month old male
DIAGNOSIS OR CONDITION:	Diagnosis of megaesophagas/tracheomalacia with swallowing and aspiration problems. Use of G-tube feeding since six weeks of age. Poor weight gain from birth to four months with a drop from the 50^{th} %ile to 5^{th} %ile. Child developed constipation problems.
INTERVENTION:	Monthly weight, length and head circumference measurements by RD at 10 home visits beginning at four months of age. Caloric, nutrient and fluid assessment of tube feeding. Recommended high calorie pediatric liquid supplement with fiber to resolve constipation. Connected with home medical supply company for tube feeding supplies. RD- Ten one hour home visits and 11 telephone contacts over 12 months.
OUTCOMES:	Resolved constipation, improvement in weight for age (10 th -25 th %ile).
INTERVENTIONS AVOIDED:	Total = \$2400 (Hospitalizations for FTT)
INTERVENTION COSTS:	Total = \$506 (Personnel \$450/year + \$56 mileage)
COST SAVINGS OF INTERVENTION:	Saved \$1894 over 12 months.

SITE:	County Health Department
CLIENT:	13 year old male
DIAGNOSIS OR CONDITION:	Cerebral palsy (spastic quadriplegia), seizures, frequent pneumonia, G-tube feeding, frequent skeletal fractures, weight loss of ten pounds.
INTERVENTION:	Developed appropriate tube feeding schedule for foster parent to follow. Increased tube feeding volume to prevent weight loss. Increased fluid. Recommended addition of calcium and phosphorous supplements. Nine home visits and 13 telephone contacts by RD over 12 month period.
OUTCOMES:	No recent skeletal fractures, weight has stabilized.
INTERVENTIONS AVOIDED:	Total = \$2055 (Two hospitalizations to assess/treat dehydration, pneumonia, skeletal fractures, and malnutrition).
INTERVENTION COSTS:	Total = \$600 (Personnel \$500 + \$100 mileage)
COST SAVINGS OF INTERVENTION:	Saved \$1455 over 12 months.

SITE:	WIC Clinic
CLIENT:	6 week old female
DIAGNOSIS OR CONDITION:	Unidentified genetic disorder associated with microcephaly. Slow growth rate and unusual facial features. Clogged tear ducts and frequent ear infections. Weight/length ratio consistently below the 5 th %ile since 6 weeks of age despite high levels of calorie intake.
INTERVENTION:	Nine monthly RD contacts since six weeks of age. Health and nutrition assessments, information on growth and development; and referrals to appropriate health services were offered.
OUTCOMES:	Nutrition counseling avoided weight loss. Began consumption of foods similar to the family.
INTERVENTIONS AVOIDED:	Total = \$2400 (Avoidance of hospitalization / evaluation for FTT and fewer infections).
INTERVENTION COSTS:	Total = \$1120 (Additional infant formula \$895/yr; personnel- \$225)
COST SAVINGS OF	Saved \$1280 over nine months.

SITE:	Home Infusion Agency
CLIENT:	5 month old male
DIAGNOSIS OR CONDITION:	Acute cardiomyopathy with congestive heart failure and gastroenteritis. Underweight (decreased from 50 th %ile to <5 th %ile weight/age) with small muscle mass. Nipple feeds but easily fatigued. Used NG feeding tube. Placement of G-tube considered. Multiple heart medications.
INTERVENTION:	Weekly home visits to provide nutrition counseling and obtain weight. Increased kilocalories of formula. Worked on feeding aversion, suggested referral to feeding clinic. RD-23 visits over six months.
OUTCOMES:	Baby able to take 100% of formula orally, 6-8 ounces at one time. Was able to begin oral feeds without feeding clinic appointment or feeding therapist. Child began self-feeding. Weight for age 5 th -10 th %ile.
INTERVENTIONS AVOIDED:	Total = \$5700 (Long term tube feeding, with G-tube placement \$5700, further malnutrition, FTT, complete oral aversion.)
INTERVENTION COSTS:	\$2900 (Of this total approximately \$633 for RD services; the remainder is RN services and daily charges for supplies, pump, bags, etc.)
COST SAVINGS OF INTERVENTION:	Saved \$2800 over six months (Note - if look just at cost of RD this savings figure becomes \$5067).

SITE:	Neighborhood Health Clinic
CLIENT:	7 month old male
DIAGNOSIS OR CONDITION:	FTT at 7 months of age. Five URIs before intervention.
INTERVENTION:	RD reviewed proper feeding techniques, feeding cues and satiety cues. Introduced solids, increased kilocalories with food choices and use of high calorie pediatric liquid supplement. RD- 8 visits over 12 months.
OUTCOMES:	Weight/height maintained at 10 th %ile for past 5-6 months. Two URIs in 12 months.
INTERVENTIONS AVOIDED:	Total = \$2615 (Hospitalizations for FTT \$2400, and continued PCP visits plus medication for URIs \$215)
INTERVENTION COSTS:	Total: \$1700 (Personnel-\$260, high calorie pediatric liquid supplement-\$1225/yr., PCP visit for URIs-\$150, medication-\$65)
COST SAVINGS OF INTERVENTION:	Saved \$915 over one year.

SITE:	CSHCN Program
CLIENT:	34 month old female
DIAGNOSIS OR CONDITION:	Encephalomalacia, shunted hydrocephalus, spastic quadriplegia, vision impairment, weight/height <5 th %ile.
INTERVENTION:	Nutrition assessments, diet and feeding analysis, and nutrition education provided by RD during home visits and early intervention center consultations. Use of high calorie pediatric nutrition supplement for 6 months. RD-11 contacts in 1.5 years at home or early intervention center. Contacts averaged 2 hours for visit, travel and written report.
OUTCOMES:	Consistent weight gain of 5-8 oz/month. Improved weight/height ratio from well below the 5 th %ile to the 5 th %ile. Diet inadequacies resolved. Provided education about WIC nutritional services that were previously resisted by the family. WIC now used by family.
INTERVENTIONS AVOIDED:	Total = \$2400 (FTT hospitalization; avoided G-tube feeding at this time. Family being educated to prepare them for eventual tube feeding).
INTERVENTION COSTS:	Total = \$1845 (Personnel, travel, mileage - \$685 and formula - \$1160)
COST SAVINGS OF	Saved \$555 over 18 months.

SITE:	CSHCN Program
CLIENT:	7 month old female
DIAGNOSIS OR CONDITION:	Arthrogryposis, status post tracheostomy. Feeding difficulties, poor weight gain, weight/height 5 th -10 th %ile.
INTERVENTION:	Monitoring of weight, length, and nutritional intake by RD. Recommended increasing caloric density of formula. Collaborated with nursing agency to provide in home pediatric scale to monitor weight. 12 RD visits over 2 years.
OUTCOMES:	Infant began showing improved weight gain which improved her strength and endurance for increased intake. Weight/height improved to 50 th %ile.
INTERVENTIONS AVOIDED:	Total = \$10,050 (Placement of feeding tube, \$5700; supplies, \$1050; formula for two years, \$3300)
INTERVENTION COSTS:	Total = \$3660 (Personnel \$360 + \$3300 formula for two years)
COST SAVINGS OF	Saved \$6390 over two years.

SITE:	CSHCN Program
CLIENT:	36 month old male
DIAGNOSIS OR CONDITION:	Encephalopathy, spastic cerebral palsy, microcephaly, seizure disorder, lack of weight gain.
INTERVENTION:	Nutrition and feeding assessment, height/weight monitoring. Formula changed to high calorie pediatric liquid supplement with fiber to better meet child's nutritional needs. Education provided on G-tube. RD-5 visits over six months.
OUTCOMES:	Weight was maintained for 6 months using a high kilocalorie pediatric nutrition supplement. Delayed placement of feeding tube for 6 months.
INTERVENTIONS AVOIDED:	Total = \$3560 (Hospitalization for FTT and malnutrition, \$2400 + supplies for 6 months feeding tube, \$260 + \$900 formula)
INTERVENTION COSTS:	Total = \$1050 (Personnel-\$150 + \$900 for nutritional supplements for 6 months)
COST SAVINGS OF INTERVENTION:	Saved \$2510 over six months.

SITE:	CSHCN Program
CLIENT:	40 month old male
DIAGNOSIS OR CONDITION:	History of prematurity, BPD, fetal exposure to cocaine. Developmental delays and FTT. NG tube-fed using formula not consumed orally.
INTERVENTION:	Monitoring height/weight, nutrition assessment and education on increasing calories for weight gain and progression of textures in diet. Recommended use of high calorie pediatric nutritional supplement. 9 RD visits over 6 months.
OUTCOMES:	Weight gain of 4 pounds over 6 months during transition from tube feeding to oral feeds. Reduced intake of high calorie pediatric liquid supplement. Progressed in self-feeding skills and in ability to eat a variety of food textures.
INTERVENTIONS AVOIDED:	Total = \$4415 (Hospitalization for FTT \$2400, long-term need for feeding tube, 6 month cost-\$265 supplies + formula \$1750)
INTERVENTION COSTS:	Total = \$930 (Supplements - \$660/6 months + personnel \$270)
COST SAVINGS OF	Saved \$3485 over six months.

SITE:	CSHCN Program
CLIENT:	29 month old male
DIAGNOSIS OR CONDITION:	Russell Silver syndrome, lack of weight gain, behavioral feeding problems.
INTERVENTION:	Monitor weight and height, nutrition assessment/education for weight gain and general feeding guidelines for age. RD-9 visits over 20 months.
OUTCOMES:	Consistent weight gain of 5-8 oz per month. Advancement of feeding skills.
INTERVENTIONS AVOIDED:	Total = \$2400 (Hospitalization for FTT)
INTERVENTION COSTS:	Total = \$270 (Personnel)
COST SAVINGS OF	Saved \$2130 over 20 months.

SITE:	CSHCN Program
CLIENT:	23 month old male
DIAGNOSIS OR CONDITION:	Tetralogy of Fallot and pulmonary atresia. Requires continuous oxygen. Weight/length at 5 th %ile, with slow weight gain. Increased caloric needs due to unrepaired cardiac defects. Constipation.
INTERVENTION:	Home visits to monitor growth, provide nutrition information on methods to increase caloric density. Began use of high calorie pediatric liquid supplement with fiber to increase energy and relieve constipation. Three one-hour home visits by RD over 8 months.
OUTCOMES:	Weight gain improved to 25 th %ile for weight/length. Activity level also increased.
INTERVENTIONS AVOIDED:	Total = \$2400 (Hospitalization for FTT and/or respiratory problems)
INTERVENTION COSTS:	Total = \$1870 (Supplements \$1530/year; personnel, travel time, and mileage \$340)
COST SAVINGS OF	Saved \$530 over eight months.

SITE:	CSHCN Program
CLIENT:	20 month old female
DIAGNOSIS OR CONDITION:	Cardiac defects, VACTERL syndrome. Lack of weight gain. Increased calorie needs due to cardiac defect, requires oxygen. Weight/length < 5 th %ile.
INTERVENTION:	Home visits to monitor growth and complete nutrition assessment/education. Carbohydrate supplement added to formula to increase caloric density. Six one-hour home visits with RD over 18 months.
OUTCOMES:	Improved weight gain (weight/length increased to >5 th %ile), increased activity level of child so she is able to interact more with her family.
INTERVENTIONS AVOIDED:	Total = \$2400 (Hospitalization for FTT)
INTERVENTION COSTS:	Total = \$975 (Supplements \$745/year; personnel, travel, and mileage \$230)
COST SAVINGS OF INTERVENTION:	Saved \$1425 over 18 months.

SITE:	CSHCN Program
CLIENT:	30 month old male
DIAGNOSIS OR CONDITION:	Down syndrome with cardiac defect, developmental delay, slow weight gain, hypersensitivity, gag reflex with oral aversion (except formula from a bottle), milk intolerance. Frequent hospital visits for asthma. Mother had been diluting formula to about 15 kilocalories/ounce to make formula last all month due to expense.
INTERVENTION:	Monitored growth and nutrient intake. Provided nutrition education on formula preparation, adding calories to accepted foods to promote weight gain, and progression to solid foods. Referred family to program to obtain additional formula to meet child's needs. RD visits quarterly over 12 months.
OUTCOMES:	Infant received more calories and gained weight. Improved weight to length ratio from below the 5 th %ile to the 5 th %ile. Child accepted oral spoon feeding of pureed foods.
INTERVENTIONS AVOIDED:	Total = \$300 (PCP visits for poor growth and asthma related illnesses, 3 visits)
INTERVENTION COSTS:	Total: \$120 (Personnel)
COST SAVINGS OF INTERVENTION:	Saved \$180 over 12 months.

SITE: Home Infusion Agency CLIENT: 11 week old female **DIAGNOSIS OR** Congestive heart failure, cardiac hypertrophy, malnutrition (weight <5th%ile). Post-surgery complications. Baby discharged CONDITION: with NG tube feeds. INTERVENTION: Mother trained to place NG tubes so baby could receive specialized concentrated infant formula which was not nippled from bottle. Increased formula volume to match weight gain and promote catch-up growth. RD updated insurance case managers on progress and conducted a weekly weight check. Contacts: 9 home visits, 3 telephone over three months. Successful transition from 50% NG feeds/50% oral to 100% oral OUTCOMES: feeds in 3 months. Steady weight gain. INTERVENTIONS Total = \$6930 (Surgery for permanent G-tube -\$5700; further malnutrition, complications with worsening cardiac condition, AVOIDED: rehospitalizations, tube feeding equipment/formula-for approximately 3 months-\$1230; non-compliance by caregiver since weekly weight gain was shown). INTERVENTION Total = \$4392 (Of this total approximately \$520 for RD services; the remainder is RN services and daily charges for supplies, COSTS: pump, bags, etc.) Saved \$2538 over three months. COST SAVINGS OF **INTERVENTION:**

SITE:	WIC Program
CLIENT:	4 year old female
DIAGNOSIS OR CONDITION:	Developmental delay, poor growth, cerebral palsy, seizure medications. Child would not chew, had a poor intake, and oral motor problems. No weight gain for one year. Caregiver showed denial, tried to feed child age-appropriate foods. Child would not take cup, fluids given with medicine dropper.
INTERVENTION:	RD provided appropriate nutritional counseling in Spanish, made appropriate referrals and contacts. Recommended high calorie pediatric liquid supplement in a bottle to increase nutrients and energy. Encouraged transition to solids based on child's developmental level. Encouraged dental care, fluoride treatments, adequate fluid intake. 4 RD visits over 14 months.
OUTCOMES:	Weight gain improved and showed catch-up growth. Developmentally appropriate intake of solids and fluids achieved.
INTERVENTIONS AVOIDED:	Total = \$2400 (Malnutrition, continued poor growth and possible hospitalization for FTT; compromised resistance, increased possibility of infections, and further need of special resources.)
INTERVENTION COSTS:	Total = \$120 (Personnel)
COST SAVINGS OF	Saved \$2280 over 14 months.

SITE:	Endocrine Clinic
CLIENT:	17 year old female
DIAGNOSIS OR CONDITION:	Insulin Dependent Diabetes Mellitus (IDDM) diagnosed at 10 years of age. Blood glucose levels were not controlled within target range. Overweight for age.
INTERVENTION:	Met with teenager every 3-6 days to revise meal plan and provide additional nutrition education regarding IDDM. She also attended group classes for IDDM. Three one hour RD visits over two weeks.
OUTCOMES:	Maintenance of blood glucose within normal limits. Avoidance of hypoglycemia/hyperglycemia episodes. Maintenance of weight. Understanding of diet for IDDM.
INTERVENTIONS AVOIDED:	Total = \$2000 (ER visit/hospitalization for diabetic ketoacidosis)
INTERVENTION COSTS:	\$325 (Personnel plus associated hospital costs)
COST SAVINGS OF INTERVENTION:	Saved \$1675 over five months.

SITE:	CSHCN Program
CLIENT:	8 year old male
DIAGNOSIS OR CONDITION:	Spastic quadriplegic cerebral palsy, feeding difficulties, poor weight gain, chronic constipation, decreased caloric intake due to feeding dysfunction. Hospitalized two times/yr., last two years for weight loss and dehydration, prior to intervention.
INTERVENTION:	Assessment and calculation of energy needs. Nutrition education to increase fiber and fluid to assist with constipation and increase kilocalories including use of high calorie pediatric nutrition supplement and a daily meal. Nutrition goals incorporated in Individualized Education Plan (IEP) with daily meals, snack, supplement and schedule. Monthly visits for two years. Current schedule is quarterly visits by RD.
OUTCOMES:	Improved weight gain of 6 lbs. in 2 years; previously had shown a weight loss of 2 lbs./year. Constipation improved from increased fiber and increased fluid intake. Increased participation in school activities.
INTERVENTIONS AVOIDED:	Total = \$15,860 (Since nutrition intervention began, \$5000 avoided for hospitalization due to weight loss/dehydration. G- tube placement avoided-\$5700 + formula \$5160 for 2 years.).
INTERVENTION COSTS:	Total = \$5880 (Nutrition supplement \$5160/2 years + RD services: 24 visits over 2 years-\$720)
COST SAVINGS OF	Saved \$9980 over two years.

CSHCN Program

SITE:

CLIENT: 14 year old male DIAGNOSIS OR Cerebral palsy and seizure disorder due to near drowning at age 6 years. Weight/height above 75th%ile, chronic constipation with CONDITION: long-term use of mineral oil, hypercholesterolemia. Was hospitalized 3 times (2 days each) over 18 months for dehydration. INTERVENTION: Diet analysis and weight monitoring. Nutrition counseling for low cholesterol, low fat diet, increasing fluid and fiber intake, and use of a vitamin/mineral supplement. Changed to diet and bowel program to avoid use of mineral oil. G-tube was placed 18 months ago for administration of medications for seizures since this adolescent was unable to take them orally. The G-tube also was used to assist with fluid intake. No foods are given through the tube. Quarterly visits/telephone consults - 12 visits plus 12 telephone contacts over 3 years. OUTCOMES: Slowed velocity of weight gain, decreased triglycerides and cholesterol levels. Weight/height down to 50th-75th%ile. Since the tube was placed 18 months ago no hospitalizations for dehydration. INTERVENTIONS Total = \$5100 (avoided use of medications to lower cholesterol-\$1500/3 yrs; avoided 3 two-day hospitalizations for dehydration-AVOIDED: \$3600 over the past 18 months.) INTERVENTION Total = \$6075 (\$375 personnel and \$5700 for G-tube placement COSTS: for medication administration and to supply additional fluids for prevention of dehydration.) COST SAVINGS OF Minus \$975 over three years. **INTERVENTION:**

SITE:	County Health Department
CLIENT:	3 year old female
DIAGNOSIS OR CONDITION:	Partial Trisomy 16q-, patent ductus arteriosus, hypotonia, inadequate nutrient intake, poor weight gain, constipation.
INTERVENTION:	Ten follow-up visits planned with WIC RD coordinating recommendations from RD at local hospital. Recommended use of concentrated calorie formula, height and weight checks, progression to nutrient dense solids.
OUTCOMES:	Improved weight gain for age; weight increased from <5 th %ile to 10^{th} %ile/age in 8 months with three RD visits. Decreased slightly to 5 th -10 th %ile for age at 30 months/fourth RD contact. Follow-up completed by the sixth contact with RD resulting in maintenance of weight at 10^{th} %ile/age.
INTERVENTIONS AVOIDED:	Total = \$10,500 (G-tube placement \$5,700, yearly supplies \$4800)
INTERVENTION COSTS:	Total = \$904 (Personnel-RD consultation completed in 6 visits over 16 months time, \$136; formula-\$576, concentrated formula, \$192 plus CHO supplement used for 7.5 months)
COST SAVINGS OF	Saved \$9596 over 16 months

FEEDING TEAM CASE STUDIES

SITE:	County Health District Feeding Team
CLIENT:	3 year old female
DIAGNOSIS OR CONDITION:	Developmental delay and continued epileptic seizures. Inconsistent oral intake, decreased oral tone. G-tube placed at 2 years for FTT and dehydration. Received 3 cans of high calorie pediatric liquid supplement at night per pump.
INTERVENTION:	Nutrition education by Feeding Team re: meal and snack schedules, increase texture of foods. Offer one can pediatric liquid supplement after meals as needed. Discontinue night G- tube feedings. Oral motor therapy for sensory input, vibration around face. One team visit. Team members: RN, RD, SLP, and parents.
OUTCOMES:	Increased oral intake, improved feeding skills, discontinued tube feedings, and increased variety of foods eaten. Weight gain maintained along 50 th %ile without tube feedings. Eats with family.
INTERVENTIONS AVOIDED:	Total = \$6300/year (Continued tube feedings, supplies & formula)
INTERVENTION COSTS:	Total = \$854 (Personnel-\$200/1 hour evaluation, formula- \$654/yr.)
COST SAVINGS OF	Saved \$5446 over one year.

SITE:	Community Feeding Team
CLIENT:	12 month old female
DIAGNOSIS OR CONDITION:	Spinal cord injury at birth, G-tube placed shortly after birth. Child seen at 4 months of age due to high risk of feeding problems and neglect but family moved from area. Family returned to area when child was 12 months of age. Child hospitalized for 12 days at 14 months of age for growth failure. Diarrhea/vomiting. Weight/height <5 th %ile.
INTERVENTION:	Feeding team follow-up after hospital discharge for growth failure. Home visits to insure accurate delivery of 24 kcal/oz feedings and address concerns including diarrhea and vomiting. Referred to WIC and early intervention program. Changed to higher calorie feeding. Total contacts over seven months: one team contact (RD, PHN, SW, OT), one case conference, and 10 follow-up contacts by a two member team which always included RD plus one other discipline.
OUTCOMES:	Increased weight/height from <5 th %ile to 75 th %ile.
INTERVENTIONS AVOIDED:	Total = \$10,600 (Avoided another hospitalization for 12 days- \$7400 and out of home placement-\$1600/month for 2 months due to growth failure and neglect.)
INTERVENTION COSTS:	Total = \$3100 (PHN-\$500, RD-\$700, SW/OT-\$400, one FTT evaluation as outpatient-\$1500)
COST SAVINGS OF INTERVENTION:	Saved \$7,500 over seven months

SITE:	Community Feeding Team
CLIENT:	8 month old male
DIAGNOSIS OR CONDITION:	34 week gestation infant, weight/height at <5 th %ile at time of first intervention. Initially failed to thrive on breast milk; oral aversion.
INTERVENTION:	Therapy to decrease oral aversion to taking liquids; increased caloric intake. One team visit with: PHN, SLP, and RD. Five follow-up RD contacts over four months.
OUTCOMES:	Weight/length ratio increased to 10 th %ile. Child able to drink from a bottle or cup and finger feed. Gained four months of skills in two months. No current developmental delays.
INTERVENTIONS AVOIDED:	Total = \$2400 (Evaluation for FTT, continued feeding problems, poor growth, developmental delay)
INTERVENTION COSTS:	Total = \$700 (Personnel)
COST SAVINGS OF INTERVENTION:	Saved \$1700 over four months

SITE:	Community Feeding Team
CLIENT:	3 year old female
DIAGNOSIS OR CONDITION:	Agenesis of the corpus collosum, developmental delay, cortical blindness, seizure disorder. Additional nutrition /feeding issues- limited self feeding skills, poor mouth closure, pocketing of food in mouth, lack of independent sitting, lack of positioning for eating. Prolonged bottle feeding with potential for baby bottle tooth decay (BBTD). Two years prior to nutrition intervention-3 incidences of gastroenteritis/dehydration (2 admits to hospital), 3 URIs requiring antibiotics.
INTERVENTION:	Recommended use of cup instead of bottle, proper positioning for feeding, identified ways to help child gain independence with feeding. Weekly therapy with OT/PT. Team members include: RD, PHN, OT, PT, and referral for single evaluation with feeding specialist. Number of visits: RD 3, PHN 2, PT weekly-over 18 months spent, approximately 12 hours, related to feeding issues.
OUTCOMES:	Coordinated care led to reduction of hospitalizations for gastroenteritis and URIs. Since intervention-no hospitalizations, no medications. Developed some independent feeding skills. Increased trust between caregivers and health professionals, reduction in time spent feeding, decreased pocketing of food.
INTERVENTIONS AVOIDED:	Total = \$4400 (At least one hospitalization for dehydration \$1200. PCP visit with meds for URIs \$100-Possible evaluation for BBTD \$100 for initial exam, if BBTD surgically treated- additional \$3,000 treatment)
INTERVENTION COSTS:	Total = \$838 (personnel, travel time, and mileage)
COST SAVINGS OF INTERVENTION:	Saved \$3562 over 18 months based on evaluation/treatment for BBTD. (Saved \$462 over 18 months without evaluation for BBTD.)

SITE:	Community Feeding Team
CLIENT:	9 month old male
DIAGNOSIS OR CONDITION:	34 week gestation infant with ongoing history of thrush, frequent URIs, developmental delay, poor weight gain (dropped from 10 th %ile to <5 th %ile weight/age), sucking problems, poor hunger cues, constipation and refusal to eat. Currently, eats a variety of infant semi-solids, drinks formula from bottle every 1.5 to 3 hours.
INTERVENTION:	Feeding team reviewed mother's concern of bottles, history of thrush, poor weight gain, poor development, and continued illnesses. Different medication was used to resolve the thrush. Recommended use of increased kilocalorie formula and proper positioning for more efficient eating. Suggestions offered to mother and day care to reduce possible thrush contamination at day care. Visits: One team-visit with RD, PHN and CDS; followup - RD-2, PHN-2.
OUTCOMES:	Thrush resolved, doctor visits decreased, developmental progress more pronounced, increased weight gain from <5 th %ile to 5 th %ile. Improvement in health for child resulted in decreased stress for mother. Decrease in PCP visits and medications allowed the mother additional family and personal time.
INTERVENTIONS AVOIDED:	Total = \$3125 (Hospitalization for FTT \$2400; PCP visits and medications for continued URIs and thrush, \$725)
INTERVENTION COSTS:	Total = \$550 (Personnel for one team and four individual contacts)
COST SAVINGS OF INTERVENTION:	Saved \$2575 over six months.

SITE:	Community Feeding Team
CLIENT:	12 month old male
DIAGNOSIS OR CONDITION:	Microcephaly, growth failure, congenital heart disease, hypotonia, severe developmental delay, autistic-like behavior. Inappropriate nutritional intake for age, inadequate growth, hypersensitivity around mouth, chewing and swallowing problems.
INTERVENTION:	Videofluoroscopy and speech evaluations. OT provided therapy for oral stimulation and hypersensitivity. Use of high calorie pediatric liquid supplement with fiber. Recommended positioning for high chair and inclusion of child at mealtime with family. Team members involved were the OT, RD, PHN, FRC, case manager, parents, and interpreter. One team visit plus monthly followup visits by RD/PHN.
OUTCOMES:	At two years of age child was following appropriate growth curve. Developmental progress made. Hypersensitivity decreased. He became interested in and approached food. Child ate with family and mealtimes were more enjoyable.
INTERVENTIONS AVOIDED:	Total first year = \$11,940 (Hospitalization for FTT \$2400; surgery for G-tube placement \$5700; supplies/formula- \$3840/yr.)
INTERVENTION COSTS:	Total = \$3840 (First year personnel \$500, supplements \$2940/yr., tests \$400)
COST SAVINGS OF INTERVENTION:	Saved \$8100 first year; \$900/yr. (\$75/month) for supplies/formula thereafter.

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SITE:	Community Feeding Team
CLIENT:	5 month old male
DIAGNOSIS OR CONDITION:	Calcification sites in brain, breathing difficulties, postnatal feeding difficulties and possible seizure disorders. Expended large amount of calories breathing and moving. Displayed oral hypersensitivity, poor suck, inability to consume adequate calories. Previously fed using G-tube which was removed. Inappropriate use of whole cow's milk mixed with corn syrup.
INTERVENTION:	Use of concentrated formula. Recommendations for positioning while feeding, stabilized chin and cheeks to improve lip closure and stabilize nipple. Attend a neurodevelopmental/early intervention program for ongoing therapy. Team members include: RD, CDS, and PHN. Visits: team 1, RD follow-up 1, continued follow-up by RD through WIC.
OUTCOMES:	Improved lip closure led to increased intake of formula. Adequate positioning led to improved intake of solid foods. Improved weight gain rate; gained 17oz in first 2 months, 22oz in second 2 months. Improved feeding skills and ability to consume slightly larger quantities. Infant's activity level increased due to increased caloric/nutrient intake.
INTERVENTIONS AVOIDED:	Total = \$6448 (Replacement of G-tube \$5,700; supplies/formula \$748/4 months)
INTERVENTION COSTS:	Total = \$912 (Personnel \$460; formula \$452/4 months)
COST SAVINGS OF INTERVENTION:	Saved \$5536 over four months.

SITE:	Community Feeding Team
CLIENT:	6 month old female
DIAGNOSIS OR CONDITION:	Transposition of great vessels of heart, weight/height <5 th %ile, poor oxygen saturation and reflux prior to corrective surgery. Easily fatigued during feeding, unable to take adequate calories. N/G tube led to oral aversion. G-tube inserted at 3.5 months.
INTERVENTION:	Weekly oral-motor therapy. Nutrition consult regarding nutrients and caloric intake. Nursing visits for family support and follow-up for nutrition recommendations. Team members: Parent, RN, SLP, OTR, and RD. Number of visits: SLP 15, RN 5, RD 3.
OUTCOMES:	Weight/height increased to 25 th %ile. Acceptance of table foods and drinking from a cup. Reflux stopped after heart surgery. Feeding skills greatly improved. Parent-child interaction more enjoyable.
INTERVENTIONS AVOIDED:	Total = \$2400 (Evaluation for FTT. Delay in corrective surgery needed for heart)
INTERVENTION COSTS:	Total = \$553 (Personnel)
COST SAVINGS OF INTERVENTION:	Saved \$1847 over six months.

SITE:	Community Feeding Team
CLIENT:	24 month old female
DIAGNOSIS OR CONDITION:	Nesidioblastosis, pulmonary artery stenosis, subtotal pancreatectomy, followed four months later by a near total pancreatectomy and gallbladder removal, G-tube placement at 3 months of age, seizures, pre-stages of heart failure treated with diazoxide and delayed/abnormal oral feeding patterns (no solids prior to second birthday).
INTERVENTION:	A consistent comprehensive dietary plan was developed with the team including parents, RD, PCP, RN, medical specialists and early intervention staff. Mother felt supported and not overwhelmed by complications which continued for child. Family learned the essentials of diet management. Three team conferences (eight hours total time) over 9 months.
OUTCOMES:	Larger variety of foods introduced to diet, and child's ability to self-feed increased. The G-tube was removed 6.5 months after feeding team intervention began. The specialized infant formula was replaced by milk products eight months after the start of feeding team intervention. Medical complications decreased; mother no longer concerned about endurance, ambulation, speech, incontinence, or oral aversion. Long distance visits to specialists decreased to one per year from one per week. Emotional and financial stresses decreased for the family.
INTERVENTIONS AVOIDED:	Total = \$14,485 (Continued home nursing service for care related to the length of feeding time - ³ / ₄ -1 hour five times daily for 4.5 months. Note: nursing services were around the clock at birth and gradually decreased over three years. Also avoided continued use of the specialized infant formula beyond 2.5 years of age.)
INTERVENTION COSTS:	Total = \$17,760 (Includes personnel/travel costs for feeding team, \$14,340 over 9 months, oral motor therapy for one year and the use of specialized formula for 8 months.)
COST SAVINGS OF INTERVENTION:	Minus \$3275 over one year.

SITE:	Metabolic Clinic
CLIENT:	11 day old infant
DIAGNOSIS OR CONDITION:	Child with phenylketonuria (PKU) diagnosed at 10 days of age; treatment initiated at 11 days of age. Interventions needed to prevent mental retardation, and support normal oral motor and cognitive development.
INTERVENTION:	Team members include RD, MD, and MSW. Nutrition: Prescription of low phenylalanine formula to meet nutrient and energy needs for growth and management of PKU, teaching formula preparation; guidance for feeding normal infant, monitoring growth, nutrient intake and blood phenylalanine concentrations. Adjustments are made to dietary prescription based on growth and phenylalanine concentration. Pediatrics: assessment of physical and neurological status. Social work: Support for payment for services, emotional support for family. Special formula-type of product used: Lofenalac, low phenylalanine medical food. Quantity needed per day or month: about 150 grams/day or 2 cases/month. Duration product needed: Until age 2, then transition to a similar medical food designed for children. Visits-14 team visits in first year of life.
OUTCOMES:	Cognitively and physically normal and healthy infant. Early identification of PKU by Newborn Screening and rigorous nutritional intervention prevent devastating mental retardation and promote normal cognitive and physical growth and development.
INTERVENTIONS AVOIDED:	Significant mental retardation (IQ-40), with eventual total care residential living (assume 65 years of residential living at \$120,000/year (\$7.8 million over lifetime).
INTERVENTION COSTS:	Total = \$5000 (Prescribed medical foods-Lofenalac: \$2400 + cost of team services-\$2600, for first year of life. It is estimated that a lifetime of effective treatment costs about \$500,000 per person.)
COST SAVINGS OF INTERVENTION:	For the first year of life, the cost saving is hard to estimate, since the child would be at home and not in residential care. However, if you used residential care costs as a base, the saving would be \$115,000 lifetime cost-benefit.

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APPENDIX A: Letters of Support

FACULTY

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Robert A. Aldrich, M.D. Patricia Hayden, M.D. Thomas H. Shepard, M.D.

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Division of Congenital Defects

December 30, 1996

To Whom It May Concern:

This letter is to strongly support the critical role that nutrition serves play in the care of children with special health care needs. In the context of providing optimal care to children with chronic illness or disability, it is my impression that nutrition services are highly cost effective.

I am a developmental pediatrician whose career has been devoted to the care of children with cerebral palsy, spina bifida, and a wide variety of other central nervous system disorders. I have always had a large clinical load as well as teaching and research responsibilities. More recently I have assumed administrative responsibilities as well. When I first started working in this setting, we had no nutrition services tailored to the needs of our children. We have subsequently acquired such services, so I can speak from first hand experience regarding the impact of a good nutritionist.

We function in a coordinated, multidisciplinary care environment. A nutritionist is always present when we are seeing children and families. The nutritionist has ongoing responsibility for responding children's needs whether they are at home, on the inpatient service, or are being seen in clinic. We also work as consultants to the primary physicians in the community who provide a great deal of the care to these children. Growth and nutrition problems have been widely documented in the literature regarding children with physical disability. Indeed, abnormalities in growth are often helpful from a diagnostic point of view. Management of these problems is crucial to optimal function. For example, a child with spina bifida and partial paralysis who becomes obese will lose motor function and require more care. As another example, a child with severe spastic quadriplegia and scoliosis will, without intervention, be undernourished. Such children are know to be much higher operative risks with increased intensive care unit and inpatient care time. Recovery is also much more prolonged.

Since we have had a knowledgeable nutritionist, we have substantially augmented our ability to deal with growth problems. We have also been able to do a much better job of providing families with the detailed and specific support that is actually needed to solve nutrition problems. It has been critical to have nutritionists who have training and personal commitment in the area. These services enable many more families to care for even severely disabled children with more independence. The use of special formulas is offset by a substantial decrease

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in acute illness and loss of function due to chronic undernutrition. If nutrition services were to disappear, we would undoubtedly see a reemergence of larger numbers of children who could not be cared for in their own homes and who would have early mortality.

The nutritionists also provide training to other professionals and raise consciousness regarding nutrition issues. Since eating is also a cultural, psychosocial, and developmental experience for children, nutrition services help children and families in many developmental domains in addition to the physiologic aspects of nutrition. Nutritional outcomes are an important part of clinical research on the effectiveness of various treatments for disabilities and chronic illnesses.

It is my strong recommendation that nutrition services be part of the core of required health benefits for children with special health care needs.

Sincerely yours,

Jóhn F. McLaughlin, M.D Professor of Pediatrics University of Washington Director, Neurodevelopmental Program Children's Hospital & Medical Center



January 13, 1997

University of Washington CHDD P.O. Box 357920 Seattle, WAS 98195-7920

TO WHOM IT MAY CONCERN:

As a Clinical Nurse Specialist involved in early intervention services for a birth to three year old population and their families, I see the role of nutrition as integral to program options. In this setting the nutritionist has readily related to other service providers including nurse practitioner, occupational therapist, physical therapist, speech therapist and educators.

From both preventive and intervention perspectives, nutrition is seen as basic to the individual child accessing other program services. Nutrient needs of children with specific syndromes, follow-up of children with gastrostomies and feeding issues related to normal growth and development lend themselves to input by the nutritionist. With medically fragile children monitoring of growth and consultation around alternative feeding options have become increasingly identified issues.

Oral-motor and feeding issues lend themselves to coordination of professional and parent perspectives. Feeding team participation has been a natural outgrowth of this collaboration, although adequate funding for that service remains limited. Despite that deterrent, Holly Ridge Center Infant/Toddler Program remains committed to providing specialized nutrition services to the families it serves. The fact that a nutritionist with specific training to meet the particular needs of this population is available positively contributes to guality care.

Sincerely,

Ware On

Patti Schroeder, ARNP Clinical Nurse Specialist

5112 N.W. Taylor Road • Bremerton, Washington 98312-8837 • Phone 360.373-2536 • Fax 360.373.4934

2-20-97

To Whom It May Concern:

My name is Chris Leavitt and I have a child who has been diagnosed with cerebral palsy, also a liver disease, Alagilles's Syndrome.

Derek has had problems from the beginning with weight gain. We have been meeting with Sharon Feucht every few months designing a food plan to fit Derek's special nutritional needs. At one point Derek's doctors were leaning towards putting a "G-tube" in Derek, but with the help and close support of Sharon we were able to help Derek gain the weight he needed. With the knowledge and tools we've learned working with Sharon, Derek has avoided another surgery which we are truly grateful for. Hopefully, continuing to meet with Sharon, I will learn how to help Derek to keep on his weight gaining road to better health.

Sincerely, Chris Leznit

Chris Leavitt

11617 SW 156th Street Vashon Island, WA 98070

January 20, 1997

To Whom It May Concern,

My daughter, Kristamae, is medically fragile. She has problems with feeding such as choking, unable to chew and sensitivity to texture. However, she enjoys food.

In the early years, she received a nutrition assessment. It identified the problems she had but didn't tell us much more than we already knew. The nutritionist did tell us about supplements that were available but expensive. No one explored resources to address the expense. There was no follow up.

We focused on therapies and special education services. Plans of treatment included how she was supposed to be positioned to eat or the type of spoon to use. No one addressed what was best to put on the spoon.

We struggled for years. Feeding Kristamae took an enormous amount of time. It took a toll on our entire family. By the time she was 9, she weighed 28 lbs even though we were feeding her 6-10 small meals a day. Problems with seizures, dehydration and constipation affected her well being. It was also costly to the managed care plan who provided health care.

I went to work for public health and found out there was a nutritionist who was trained for children with special health care needs. At no cost she came for a home visit. She educated us and helped work out a plan that made sense for our family. She suggested vitamins and a calcium supplement for her expected bone loss.

Kristamae did have a G-Tube placed that year. I remember how tough the decision to place the tube was to make. The outcome was worth it.

At first she was fed with a formula through the tube only. She progressed to oral foods. A nutritionist became part of the team to plan Kristamae's services. In fact, we won't meet without the nutritionist involvement. Today the tube is used for medicine, additional fluids and during occasional illness to prevent weight lost. She is 15 and weights 100 lbs. She is much happier and more importantly healthier. She enjoys meal times with her family. The enormous stress from not knowing how to meet Kristamae's unique nutritional needs is gone.

I would like to make a few points regarding nutritional services for children with special health care needs:

- Educate parents early on to the importance of nutrition.
- Nutritionist be included in a team approach when planning services.
- Cost effectiveness can be achieved through a long term approach.
- Resources and benefits need to cover nutritional services.
- Provider education on the importance and resources re: nutrition.
- Home visiting is critical for the nutritionist to see the full picture. Considering the child in context of the family where culture and tradition effect nutrition. Family is the constant in caring for a child with special health care needs.

The importance of nutritional services are crucial to good health for anyone. Nutrition is critical for children with special health care needs and it takes expertise to address those unique needs.

Please contact me at 206-527-5709 if you have further questions regarding the importance of nutritional services for children with special health needs.

Sincerely,

Kate Willey

Kate Willey

APPENDIX B: Case Study Collection Forms

CSHCN Nutrition Cost Savings Case Studies

Site:		
Patient/Problem		
Patient description:		
Medical problem precipitating nutritional risk: _		
Nutrition problems:		
RD Intervention		
Describe the RD treatment:		
Number of visits:		
Special Formula/Nutrition Supplement		
Type of product used:		
Quantity needed per day or month:		
Duration product needed:		
Health Outcome:		
Complications Avoided:		
Resources Saved:		
Intervention Cost		
Actual charges for nutrition supplements:		
Approximate costs of RD services:		
Intervention Benefit/Cost Savings:		
Completed by:	Date:	

Nutrition Cost Savings Case Studies

Site:

Describes the practice site and city in Washington.

Patient/Problem:

Describes the patient (age, sex), medical problem/diagnoses precipitating nutritional risk, current health status, and the current status of nutrition and feeding problems.

RD Intervention:

Describes the nutrition intervention and therapy plan and the number of visits.

Special Formula/Nutrition Supplement:

Describes the type of product used, the quantity needed per day or month, and the duration the product needed.

Health Outcome:

Describes the positive health benefits resulting from the nutrition intervention and nutrition supplementation, such as improved clinical markers, improvement in current illnesses, reduction in medications.

Complications Avoided:

Describes what was likely to happen to the patient without the nutrition intervention and supplementation, such as surgery, hospitalization, medical visits, illnesses.

Resources Saved:

Describes the estimated expense of the alternative treatments and complications that were avoided.

Intervention Cost:

Actual charges for nutrition supplements, approximate costs of nutrition services.

Intervention Benefit/Cost Savings:

Cost of RESOURCES SAVED minus INTERVENTION COST.

Return completed forms to: Maria Nardella, MA, RD Nutrition Consultant Office of Children with Special Health Care Needs P.O. Box 47880 Olympia, WA 9B504-7880 Phone: 360-236-3573 FAX: 360-586-7868

Feeding Teams Cost Savings Case Studies			
Site:			
Patient/Problem			
Patient description:			
Nutrition and feeding problems:			
Feeding Team Intervention			
Describe the intervention:			
Team members involved:			
Number of visits:			
Special Formula/Nutrition Supplement			
Type of product used:			
Quantity needed per day or month:			
Duration product needed:			
Health Outcome:			
Quality Outcomes:			
Complications Avoided:			
Resources Saved			
Intervention Cost			
Actual charges for nutrition supplements:			
Approximate costs of team services:			
Intervention Benefit/Cost Savings:			
Completed by:	Date:		

Feeding Teams Cost Savings Case Studies

Site:

Describes the practice site and city in Washington.

Patient/Problem:

Describes the patient (age, sex), medical problem/diagnoses precipitating the feeding problems, current health status, and the current status of nutrition and feeding problems.

Feeding Team Intervention:

Describes the feeding team intervention and therapy plan, the team members involved, and the number of visits.

Special Formula/Nutrition Supplement:

Describes the type of product used, the quantity needed per day or month, and the duration the product needed.

Health Outcome:

Describes the positive health benefits resulting from the team intervention and nutrition supplementation, such as improved clinical markers, improvement in current illnesses, reduction in medications.

Quality Outcome:

Describes the positive impact on the child and family, such as improvement in feeding skills, reduction in feeding time, reduction in special equipment and supplies, coordinated care and treatment recommendations, reduction in fragmented clinic visits and mileage.

Complications Avoided:

Describes what was likely to happen to the patient without the team intervention and supplementation, such as surgery, hospitalization, medical visits, illnesses.

Resources Saved:

Describes the estimated expense of the alternative treatments and complications that were avoided.

Intervention Cost:

Actual charges for nutrition supplements, approximate costs of team services.

Intervention Benefit/Cost Savings:

Cost of RESOURCES SAVED minus INTERVENTION COST.

Return completed forms to: Maria Nardella, MA, RD, Nutrition Consultant Office of Children with Special Health Care Needs P.O. Box 47880 Olympia, WA 98504-7880 Phone: 360-236-3573 FAX: 360-586-7868



