Meeting the nutritional needs of children with disabilities and their families

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Meeting the nutritional needs of children with disabilities and their families

by

Christine A. Secrist-Mertz

A Dissertation Submitted to the

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GENERAL INTRODUCTION

The survival rate of children with health care needs has increased over the past decade. Premature infants weighing less than 1,000 grams are able to live (Lucas, 1987). Some of these infants require specialized technological assistance, such as ventilators or feeding tubes, are delayed developmentally, and have chronic medical problems. These advancements within the medical field have resulted in infants who may require specific medical and nutrition intervention. Early intervention is one avenue for addressing the needs of these children. As early intervention services for infants with disabilities have increased, the need for qualified personnel to meet these needs has likewise increased. Congress has sought to address the feeding and nutrition needs of children with disabilities and specialized health care needs by including nutrition under Public Law 102-119, the reauthorization of the Individuals with Disabilities Education Act. Nutrition is one of twelve disciplines included on the teams providing early intervention services to young children with disabilities and their families.

Currently many schools do not have qualified professionals to meet the needs of children with disabilities, despite the need for the services and the implied mandate to services through PL 102-119 (Rokusek, Prendergast, & Ekvall, 1993). Oftentimes professionals lack knowledge in working with the families having a child with disabilities and specialized feeding procedures. Families vary in their ability to live with a child who has compromised nutritional status and professionals need knowledge to perceive and explore individual family values and issues (Stevenson, Gressard, Kocher, & Bella, 1993). Professionals require knowledge to work in partnership with families before a child with disabilities becomes severely malnourished or medically compromised as a result of inadequate nutrition.

Nutrition intervention services include using a feeding tube, food and liquid modifications, oral-pharyngeal precautions such as increased calories, thickened liquids, changes in food textures, or precautions for aspiration. The outcomes of nutrition intervention
services for children with disabilities and their families is limited. In a study by Cross, Oakland, Brotherson, Secrist-Mertz, & Linder (1994) it was demonstrated that there was a positive relationship between physical growth and parental perception of nutrition services. Fifty nine percent of the children involved with nutrition intervention services, achieved an increase in weight for height ratios. In addition, more than one third of the parents indicated that intervention was helpful in meeting their child’s nutritional needs. The data supports the need for school-based nutrition services.

Children with disabilities who are at risk for poor nutrition and health problems, are impaired in their ability to learn (Ault, M., Guy, B., Rues, J., Noto, L., & Guess, D., 1994). General characteristics of children receiving poor nutrition include lethargy, decreased levels of energy or stamina, and poor attention span. Severe malnutrition places children at risk for development of sores, injury, poor oral hygiene, constipation, vomiting, and diarrhea (McCamman & Rues, 1990). These characteristics clearly have a direct impact on the child’s ability to function in both the home and school settings. The interaction between proper nutrition and increased capacity to learn are important components that need to be addressed through early intervention services.

Addressing the needs of these children is not an easy task. Feeding a child with nutritional problems is a complex activity. The physical characteristics of the child greatly affect the child’s ability to eat. This particular facet of feeding emphasizes the mechanical process of getting adequate nutrients. Getting the child to eat is not only dependent on the physical characteristics of the child, but also depends on how the child is fed, who feeds the child, what the child’s food preferences are, and family issues of stress and support. Having an integrated model for professionals to work from would assist the multidisciplinary teams in better understanding the needs of children with disabilities and nutritional problems. Current literature does not support the use of an integrated approach in addressing the nutritional needs for children with disabilities and their families.
For some children who have difficulty receiving adequate nutrition, families will be faced with the decision to place a feeding tube in their child (Bear, Farnan, & Mauer, 1991). This decision might include meeting nutritional needs by enteral feeding through a gastrostomy tube surgically inserted directly into the stomach or small intestine (Rempel, Colwell, & Nelson, 1988). While there is evidence that child health and quality of life can improve with the use of a feeding tube, parents oftentimes face a difficult challenge in this decision making process. When making the decision, families must consider that for many children with severe disabilities, the gastrostomy tube will be inserted for feeding and nourishment over a prolonged period of time or permanently.

The decision making style for families with children with disabilities vary greatly (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). For families of children with disabilities and inadequate nutrition, decisions may be made with varying degrees of risk, uncertainty, and conflict. These decisions may be made with uncertainty about changes in quality of life, sometimes made in disagreement with professionals, and oftentimes made with fears of negative outcomes (Campell, 1988; Hoyt, 1992; Stevenson, Gressard, Kocher, & Bella, 1992).

Gaining more knowledge about the impact of nutrition intervention services for children with disabilities and their families will give professionals a stronger foundation to work in partnership to meet the needs of these children. The two studies in this dissertation seek to facilitate an understanding of the effects of nutrition intervention services for a child with disabilities and their family. The first study used an integrated model to examine the impact of nutrition intervention services for children with disabilities and their family. The model involved three elements: physical characteristics of the child, interaction between the child and parent, and child behavioral issues associated with feeding.
The following research questions were addressed:

* What are the physical and nutritional characteristics of children with severe disabilities and underweight status?
* Did the nutrition intervention program improve the physical and nutritional status for the children in the study?
* How do issues of parent stress and social support relate to children with severe disabilities and underweight status?
* What changes did the parents describe in their child as a result of the nutritional program?
* How has the child’s eating behavior affected the parent and child interaction?
* What is the relationship between the child’s behavioral problems and level of disability?

Data were collected using a variety of sources and analysis was done using The Statistical Analysis System (The SAS Institute Inc., 1990).

The second study used a qualitative design. Qualitative methodology was selected in order to understand the multiple perspectives, experiences, and emotions described by the parents. Interviews with eight families allowed the researchers to understand how families of children with severe disabilities and special health care needs gave meaning to difficult or sensitive experiences related to feeding and nutrition of their child with severe disabilities. The following research questions were addressed:

* What are the issues families face in making a decision to place a feeding tube in their child?
* What do parents identify as concerning quality of life in relation to the placement of feeding tube?
* How can professionals support families in making this health care decision for their child?
Both studies will give professionals more knowledge in working with children with disabilities and their families. The outcomes of the studies will add to the current body of knowledge and support the use of an integrated perspective in addressing the nutritional needs of children with disabilities and their families.

**Dissertation Organization**

This dissertation contains two papers. The first paper will be submitted to the *Journal of Association for the Care of Children’s Health*. The graduate student was the primary author on this paper. The student was an active member of a collaborative research team that met regularly over a two year period. Data collection, analysis, and interpretation of results were primarily done by the graduate student. The graduate student developed the model upon which this paper is based. This integrated model of feeding and nutrition examines three primary elements that affect a child’s nutritional status.

The second paper has been accepted by the *Journal of the Association of Persons With Severe Handicaps* (In press). This paper was primarily written by the first author. In the second paper, the graduate student was also an active member of the research team. This research team met weekly over a two year period, to organize and discuss ongoing data collection. The graduate student participated in the data collection by conducting interviews with families, conducted data analysis, addressed issues of research stability and consistency, and assisted in the writing of results specifying categories that emerged from the data. The graduate student also presented this research at two national professional conferences and one state professional conference. The graduate student’s involvement helped facilitate interpretation of data to identify emerging themes and issues.

References, figures, and tables follow each paper. The general conclusion section contains a summary of the results from both papers and a discussion of the results as they apply to the larger problem of nutritional issues for children with disabilities and their families.
The conclusion section also addresses the implications for family therapists who work with children who have major nutritional needs.

References


CHAPTER 1
THE USE OF AN INTEGRATED MODEL IN MEETING THE NUTRITIONAL NEEDS OF CHILDREN WITH DISABILITIES AND THEIR FAMILIES

A paper to be submitted to the Journal of the Association for the Care of Children’s Health
Christine Secrist-Mertz, Mary Jane Brotherson, Mary Jane Oakland, & Ruth Litchfield

Abstract
Children with disabilities need adequate nutritional intake to survive and thrive. Many are at risk and in need of nutritional intervention. This study evaluated the outcomes of nutritional services for children with disabilities their families. Thirty-five children and families who received nutritional intervention services participated in the study. An integrated model of feeding associated with disabilities was developed to examine the findings. This integrated approach in addressing the nutritional needs of children with disabilities and their families was supported by the data. Children with disabilities and inadequate nutrition significantly benefited from nutrition intervention services. Children increased in weight and height ratios. Families reported increased alertness for their child, increase in stress, and decrease in social support. These findings can help families and professionals work in partnership before a child becomes severely malnourished or medically compromised as a result of inadequate nutrition.

Introduction
Adequate nutrient intake is essential for survival and development of the human child. The well-nourished child is likely to grow at an expected rate, have an increased capacity for learning, be able to resist infections, and have the energy to participate in activities (JADA, 1990). Children with severe disabilities have many of the same basic requirements as other children for nutrient intake and some may even have increased requirements (Ault, Guy, Rues, Noto, & Guess, 1994). Risk factors, however, associated with genetic and or metabolic disorders, birth defects, infections, perinatal drug exposure, or handicapping condition, impair
the nutritional status of 10% to 25% of the pediatric population (Baer, Farnan, & Mauer, 1991). Nutrition intervention is viewed as an essential health service to enable children with disabilities and chronic illnesses to attain maximum potential and quality of life. Nutritional intervention is also essential to help families respond to and meet the feeding and nutritional needs of their child.

The impact of nutrition services for children with disabilities is ongoing and lifelong. Congress has sought to address the feeding and nutrition needs of children with disabilities by including nutrition under Public Law 102-119, the reauthorization of the Individuals with Disabilities Education Act. Nutrition is one of twelve disciplines included on the teams providing early intervention services to young children with disabilities and their families. Currently, many schools do not have qualified professionals to meet the nutritional needs of children with disabilities, despite the need for services and the implied mandate for services through Public Law 102-119 (Rokusek, Prendergast, & Ekvall, 1993). There is a lack of supportive documentation outlining how school based nutrition services are beneficial to the child and family.

In a study by Cross, Oakland, Brotherson, Secrist-Mertz, & Linder (1994), it was demonstrated that there is a positive impact on physical growth for children with disabilities and increased positive parental perceptions of nutrition services. In Cross et al. (1994), it was reported that 59% of the sample achieved an increase in weight for height ratios after nutrition services. In addition, more than a third of the parents indicated that intervention was helpful in meeting their child’s nutritional needs. The Cross et al. (1994) study supports the idea that school based nutrition services do have a positive impact on the child and family.

In a position paper by Ault et al. (1994), it was discussed that children with disabilities who are at risk for poor nutrition and health problems are impaired in their ability to learn. The interaction between proper nutrition and increased capacity to learn are important components
that need to be addressed in the child’s educational plan. Discovering how and who will address these issues is not well researched.

One of the problems in addressing feeding problems for children with disabilities, is the lack of an integrated model that takes into account a variety of elements that may affect the child’s nutritional status. This study presents an integrated model of feeding and nutrition for children with disabilities and discusses how the elements of the model relate to school based nutrition services. The results have implications for improving the quality of nutritional services for children with disabilities and their families (see Figure 1).

An Integrated Model of Feeding Associated with Disabilities

Feeding a child with nutritional problems is a complex activity that involves an interaction of three elements: physical characteristics of the child, interaction between the child and parent, and child behavioral issues associated with. Feeding programs that focus only on getting food into the child deal exclusively with the physical aspects of nutritional problems (Humphry, 1991). The relationship between the child and parent, along with the child’s behavior when eating, may also have an impact on whether the child will benefit from nutritional services. Understanding how these three elements relate to one another and to adequate nutrient intake is not clearly defined. The use of an integrated model which includes these three elements and how they relate to adequate nutrient intake, would assist professionals in better meeting the nutritional needs of children with disabilities and their families ( refer to Figure 1). Currently there is a lack of research supporting the use of an integrated model when examining the nutritional needs of children with disabilities and their families. The following is
a discussion of an integrated model and how each element in the model relates to adequate nutrient intake.

**Physical/Nutrition Status**

Physical abilities and characteristics of the child greatly affect the child’s ability to eat. This particular facet of feeding emphasizes the mechanical process of getting adequate nutrients into the child. Difficulty in swallowing has been found to be a primary risk for feeding and malnutrition (Smith, 1989). Neurologically impaired infants and children suffer from poor postural control and body extension that contribute to jaw thrust, making it difficult for the child to suck or close the mouth for eating (Cloud, 1993). Almost all types of disabilities are associated with nutrition problems (Baer, Franan, & Mauer, 1991). Inherited diseases such as cystic fibrosis, PKU, and maple syrup disease require specific nutrition modifications and interventions (Crump, 1987). Congenital anomalies also have nutritional implications. These disabilities can affect the structure and function of the gastrointestinal tract in such a way as to require special feeding approaches (Crump, 1987). Cleft palate and lip, spina bifida and skeletal anomalies resulted in unique nutrition and feeding requirements due to body structure and activity level (Farnan, 1993).

Children with severe cerebral palsy and mental retardation represent the largest challenge due to oral-motor dysfunction and problems with feeding. Nutritional problems resulting from early feeding difficulties often lead to stunted growth, complications in chronic health and developmental conditions, and impaired child and parent interactions (Hine, Cloud, Carither, Hickey, & Hinton, 1989).

There are a growing number of babies born to drug addicted and HIV positive mothers who have unique and complex feeding and nutritional needs. Drug-related effects on the fetus are a result of the direct action of the drug itself, or the secondary effect related to the mother’s drug addiction (Rice-Asaro, Wasek, Franklin, & Dixon, 1990). These effects may interfere with the child’s ability to take adequate nutrition, as well as impact on the overall nutritional
status of the drug-effected child. Lack of knowledge about the behavioral and physical characteristics of infants born under these conditions are creating difficulties in assessing both nutritional needs and outcomes for this population (Rice-Asaro et al., 1990).

**Parent and Child Interaction**

Meal time interactions can influence many aspects of the child’s ability to eat (Lane & Cloud, 1988). Total body-muscle tone, body positioning, and oral motor skills can be influenced by the feeding relationship between the parent and child. Frequently, parents are responding to extensive and unique care-taking demands that may inhibit their quality of interaction while feeding their child (Beckman, 1983).

Many families experience stress in caring for a child with severe disabilities and related health problems (Stevenson, Gressard, Kocher, & Bella, 1992). Families having a child with disabilities deal with a variety of stressors relating to the care and health condition of the child. Families with children having chronic health problems are oftentimes faced with the possibility of death, which causes stress for the whole family. Many of these children require special feeding routines. These unusual care giving demands can contribute to the distress many families experience (Harris & McHale, 1989). These families not only experience increased stress, but also less social support from family and friends in dealing with a child with disabilities and health care problems. Kazak & Marvin (1984) in a study of social networks of families of children with disabilities found that the social support of these families were significantly smaller than those of comparison families.

There are other factors influencing the interaction between the child and parent in addition to stress. Children with disabilities rely on environmental cues to obtain their needs (Crump, 1987). Parents may misinterpret cues that the child provides during feeding, thus interfering with food intake. Therefore, it is important for the parent to be aware of environmental cues that may inhibit the feeding process (Cloud, 1993).
Child Behavioral Issues Associated With Feeding

Getting the child to eat is not only dependent on the physical abilities of the child and the interaction between the child and parent, but also involves specific child behavioral issues, as well. Behaviors such as refusing to eat, non-acceptance of certain food items, inappropriate dietary habits, and strong preferences can complicate the feeding process and inhibit adequate nutritional intake.

Typical behaviors of children with disabilities who display food refusal and strong preferences are agitation, turning their head away when food is presented, temper tantrums, throwing food and utensils, spitting food, and vomiting (Luiselli, 1994). These behaviors may begin at the introduction of mealtime cues, such as, placing food and utensils on the table, placing the bib on the child, and taking the tray off the high chair. Behavior problems associated with feeding can lead to malnutrition, dehydration, and weight loss (Luiselli, 1994).

Treatment of behavioral problems associated with feeding include behavior interventions with positive and negative reinforcement schedules. In one study by Luiselli (1994), treatment for two children involved a non-aversive stimulus controlled approach, whereby feeding “demands” were eliminated from meals so as not to provoke resistance or agitation. Pleasurable stimulation was made available on a non-contingent and then contingent bases, and requirements for oral consumption were introduced gradually. This intervention for the two children in the study produced positive effects of increased weight and oral consumption.

For some children with severe disabilities, eating may represent one aspect over which they have control. Refusing to allow certain foods to be placed in the mouth is a way for the child with a disability to feel in control of themselves and their environment. This issue of control can impact the interaction between the child and family (Schloss, Alper, & Jayne, 1993).
Family members become distressed because the child is not eating, not gaining weight, and shows physical signs of malnutrition. This interactional sequence is indicative of child behavioral issues that need to be taken into account when addressing the nutritional needs of children with disabilities. Parent behavioral issues must also be addressed. Parents may not be able to, or willing to, make diet modifications for their child, thus affecting the outcome of nutrition services (Satter, 1986).

Integrated Research Questions

Research related to specific nutritional needs of children with disabilities and the impact on families has been limited (Cloud, 1993). As the importance of nutrition services in improving the quality of life for children with disabilities and their families is increasingly recognized, there is also a need for an integrated research approach to these services. This study addressed the following research questions:

Physical and Nutritional Status

1. What are the physical and nutritional characteristics of children with severe disabilities and underweight status?
2. Did the nutrition intervention program improve the physical and nutritional status for the children in this study?

Parent-Child Interaction

1. How do issues of parent stress and social support relate to children with severe disabilities and underweight status?
2. What changes did parents describe in their child as a result of the nutritional program?

Child Behaviors Associated With Feeding

1. How has the child’s behavior affected the parent and child interaction?
2. What is the relationship between the child's behavior problems and level of disability?

Method

Participants

In 1990, an interdisciplinary and interagency coalition between two hospitals (Iowa Methodist Medical Center and University of Iowa Hospital School and Clinics) and an urban school system (Des Moines Public Schools) responded with efforts to address the nutritional needs of children with disabilities and their families. In the first year of the program, a registered dietitian became an on-site member of an existing public school intervention team. In the second year of the program, researchers from Iowa State University were added to the project to provide an evaluation and research component. This study is one of several studies that were used as the evaluation and research component of the nutrition program.

The school intervention team included a registered dietitian, occupational therapist, social worker, speech pathologist, physical therapist, and a nurse. Services were provided to children and youth with developmental disabilities from birth to age twenty-one (Cross et al., 1994). A referral system was established for school staff to identify children with nutritional risk factors warranting nutritional services. These services were provided by the intervention team. The participants for this study were children and families who received nutritional services from the school intervention team. Referrals for nutrition services were made by school personnel, parents, physicians, and community agencies. In response to the referrals, the dietitian, with other team members, conducted a comprehensive nutrition assessment that included: (a) review of the child's cumulative school record; (b) comprehensive literature review of varying diagnoses; (c) interviews with parents, school personnel, and alternative caregivers; (d) nutrition analysis of intake; (e) assessment of serial growth parameters; (f) drug-nutrient interaction screening; (g) meal and snack observation; and (h) evaluation of oral-motor
development. The nutrition assessment was shared with the team, including the family, for establishment of a comprehensive intervention plan. At the conclusion of the assessment process, recommendations were discussed and implementation strategies were delivered by the team to each child in this study.

A family survey, along with a cover letter describing the study, was sent to 46 families who were receiving nutrition intervention services. Initially, 63% (29) of the families responded. Follow-up letters and telephone calls increased the response rate to 76% (35). Several families declined to participate in the study, while other families were not reached as they did not have a telephone and did not respond to the second mailing.

Thirty-five children and families participated in the study. Forty-six percent of the children were involved in school programs for children 6 to 14 years of age. Fourteen percent (5) participated in a preschool program (4 and 5 year olds), while 37% (13) were in the birth to 3 year old program. The children ranged in age from 13 months to 14 years, with a mean of 7 years. Fifty-one percent (18) of the children were female, while 49% (17) were male (refer to Table 1).

The types of disabilities included mental retardation, cerebral palsy, autism, Rett Syndrome, Down Syndrome, developmental delay, spina bifida, chromosomal disorder, and nemaline myopathy. The majority of children also have a seizure disorder. The children’s disabilities ranged from mild to profound as rated by the interdisciplinary team (nutritionist, school registered nurse, and occupational therapist). Sixty-nine percent (24) of the children were severe/profoundly disabled, while 11% (4) and 20% (7) fell into the mild and moderate ranges respectively.
Eighty percent of the children in need of nutrition intervention services fell below the 5th percentile based on weight for height. Nutrition intervention fell into two categories; 1) support for underweight children (29%) (11) requiring gastrostomy tube feeding, and 2) support for underweight children (71%) (24) requiring food and liquid modifications, oral-pharyngeal precautions such as increased calories, thickened liquids, changes in textures or precautions for aspiration. Parents in both categories were offered suggestions and training in appropriate ways to feed their child and/or make diet modifications. The average length of intervention was 16.5 months.

The families involved in this study can be characterized as Caucasian, primarily two parent households (Refer to Table 2). Single parent families made up 34% (12) of the sample. Most of the children were cared for by a biological parent, with only three children (9%), living in a community program. The majority of the mothers were not employed and received financial support services such as Aid to Dependent Children, food stamps, and/or Medicaid. Eighty-three percent (29) of the families had more than one child.

Data Collection Procedures
The following instruments were used in collecting the data:

Feeding Scale: The Feeding Scale was developed by the occupational therapist on the team and is based on her experience in working with children with disabilities and feeding problems (Frolek Clark, 1994). The Feeding Scale was a descriptive measure used to categorize the feeding behavior of the children according to the following variables: (a) food modifications; (b) liquid modifications; (c) proportion of meals fed orally or by a gastrostomy tube; (d) amount of caregiver assistance required in feeding; and (e) oral-pharyngeal
To increase content validity, pilot field testing of the scale was completed with five children with disabilities and nutritional problems. A sub-component of the scale included a category of behavior problems related to feeding. Behaviors included refusal to eat, non-acceptance of food items, inappropriate dietary habits, and strong preference for certain food items. The interdisciplinary team assigned each child a rating on the Feeding Scale. The rating ranged from 1) adequate feeding function to 6) severe III dysfunction—generally has feeding tube. Each child was simply identified (yes/no) as having behavior problems associated with feeding.

**Weight for Height Assessment.** Weight for height assessment examines the child to ascertain if weight is proportional for height. All of the children were weighed and measured for height while receiving intervention services. The dietitian or school nurse collected the data monthly. To decrease the chance of error associated with the measurement, consistent protocol (i.e. shoes off, use of same scale) was used in weighing each child. For purposes of this study, two measurements were used: (a) the beginning percentile of weight for height (time one); and (b) the percentile of weight for height at the end of the study (time two).

**Family Survey:** Information concerning the families was collected using the Family Survey. This instrument was developed specifically for this study. The parent or caretaker filled out the survey. The survey consisted of four questions pertaining to the following: (a) feeding relationship between the parent and child; (b) stress as it related to the feeding process; (c) family social support in relation to the feeding process; and (d) the child’s level of alertness following nutrition intervention. Families were asked to respond to questions in these areas.
using a 10 point Likert Scale. The four questions were: How well do you feel the school has successfully met the nutritional needs of your child? How stressed are you in meeting the nutritional needs of your child? How helpful are relatives and friends to you in meeting the nutritional needs of your child? How would you rate your child's overall alertness and responsiveness since beginning the nutritional program? In addition, open-ended questions about the feeding process and the parents' perceptions of nutrition services were gathered. Parents were asked how long it took to feed their child each day and how many meals they fed their child. This was a descriptive study, therefore further research is needed to establish reliability and validity of this instrument.

Analysis

Data from the survey, weight and height measurements, and ratings on the Feeding Scale were all entered into the computer. Correlation's, paired t-test, and F-test were generated using the Statistical Analysis System (The SAS Institute, Inc., 1990). Content analysis of parents' responses to the open-ended questions on the family survey were also conducted. The use of two coders were used to reduce potential bias that can result from one investigator working alone (Stainback & Stainback, 1988). The first investigator read through the responses and categorized them separately, while the second investigator did the same. Categories emerged from the data. Differences in interpretation between the investigators were resolved by reviewing the responses to support or to eliminate possible interpretation. Using these procedures, a 91% interrater agreement rating between the two investigators was achieved.

Results

The integrated model of adequate nutrition takes into account three elements associated with feeding: (a) physical characteristics of the child, (b) parent and child interaction, and (c) child behavioral issues. This framework will be used to report the findings (see Figure 1).
Physical Characteristics of The Child

Variables related to the physical characteristics of the child include: (a) change in weight; (b) level of disability; (c) child's rating of alertness; and (d) type of feeding route (gastrostomy tube fed or non-gastrostomy tube fed).

The child's weight for height percentile at the beginning of nutrition intervention (time 1) and the child's weight for height percentile at the end of this study (time 2) were compared using a paired t-test. The beginning weight for height percentile mean (time 1) was 7.65, while 24.8 was the mean percentile for time 2. The change in weight for height percentile mean was 17.1. A significant difference between the two means was found (t=4.81, n=34, p<.0001). The nutrition intervention program resulted in significant weight gain for those children with disabilities.

Another child physical characteristic that was examined was the level of disability. Disability included three levels; (a) severe/profound; (b) moderate; and (c) mild mental retardation. A simple correlation between the child's level of disability and change in weight for height percentile was not significant (r=.173, n=35, p<.328). This indicates that no significant differences for change in weight for height percentile gain were found among the three levels of disability.

Spearman's correlation between the number of meals the child received each day and the parent's rating of the child's level of alertness was found to be significant (r=.348, n=32, p<.05). Children who were fed more often were rated as more alert by their parent. A simple correlation between the type of intervention, whether the child was fed orally or by a gastrostomy tube, and the parent's rating of the child's level of alertness was significant (r=.339, n=32, p<.05). To further examine which group demonstrated higher levels of alertness, an analysis of variance was performed. There was significantly higher levels of alertness for gastrostomy tube fed children than for orally fed children (F (1,30) 3.97 p<.05).
This indicates that children with gastrostomy tubes were more likely to be rated higher on alertness by their parent than children who did not have gastrostomy tubes.

The type of feeding route was also correlated with the number of meals the child received each day, producing a significant correlation \( r = .422, n=35, p<.01 \). An analysis of variance detected significantly more meals per day for gastrostomy tube feed children as compared to non-gastrostomy tube fed children \( F (1,33) 6.44 p<.01 \). In other words, gastrostomy tube fed children were fed more often than non-gastrostomy tube fed children, and demonstrated higher levels of alertness as noted by their parents.

The child's rating on the Feeding Scale and the total time spent feeding the child each day, as reported on the Family Survey, was positively correlated \( r = .631, n=33, p<.0001 \). Children who have greater physical, oral-motor dysfunction take longer for families to feed. There also was a negative correlation between the child's rating on the Feeding Scale and the level of social support for these families \( r = -.438, n=32, p<.01 \). Those children who have increased physical, oral-motor dysfunction had decreased family social support.

Five categories were generated through content analysis of the open ended question on the Family Survey: What changes have you seen in your child since beginning the nutrition intervention program? The largest category was positive physical changes (36.3%). This category included the following: (a) increased activities, 12.7%; (b) improved mental abilities, 10.9%; (c) better appetite, 7.3%; (d) hunger needs met, 3.6%; and (e) healthier appearance, 1.8%. The second largest category was weight gain (34.5%). Figure 2 reports the other categories and percentages.

Insert Figure 2 about here
Parent and Child Interaction

Variables within this element of the model include: (a) parental stress; and (b) family social support. There was a positive correlation between the total time each day it took to feed a non-gastrostomy tube fed child and the parent's reported level of stress ($r=.348$, $n=24$, $p<.10$). Therefore, children who did not have a gastrostomy tube and required more feeding time had parents who reported higher levels of stress. The number of meals a child received each day was negatively correlated with the level of social support reported by the parents ($r=-.445$, $n=32$, $p<.01$). Children who required more meals had parents who reported less social support. There was a negative correlation between the type of feeding route (non-gastrostomy tube fed children and orally fed children) and the level of social support ($r=-.339$, $n=32$, $p<.05$). Children with gastrostomy tubes had parents who reported lower levels of social support compared to children who were non-gastrostomy tube fed.

Eight categories were generated through content analysis of the open ended question as stated on the Family Survey: What has been most stressful for you in meeting the nutritional needs of your child? The largest categories were difficulties in the child's participation with the feeding routine (24.0%) and getting the child to eat enough (24.0%). The second largest category was meal preparation (16.0%). Other categories and percentages are reported in Figure 3.

Child Behaviors Associated with Feeding

Variables within this element of the model include: (a) behavior problems with the child while eating; and (b) parental stress. A comparison between the mean level of stress for parents of children with behavioral problems associated with feeding and the mean level of stress for parents of children without behavior problems was done using an F-test. The mean
level of stress for the first group was 7.33, while the mean level of stress for parents of children without behavior problems was 4.96. The F-test difference between the two means was marginally significant (F (1,23) 2.62 p<.12). This indicates that parents having children with behavioral problems associated with feeding reported higher levels of stress.

A partial correlation between the child's level of disability and behavioral problems associated with feeding, while controlling for the child's rating on the feeding scale, produced a positive correlation between the two variables (r=-.499, n=26, p<.01). Those children who are mildly disabled were more likely to have behavior problems associated with feeding.

Discussion

The Individuals with Disabilities Education Act (IDEA), Part H, includes nutritionists as members of the interdisciplinary team, to serve children birth to three with disabilities and their families. This study supports their role on the team by documenting the significant positive increase for children in height and weight when nutrition intervention is appropriately delivered. This was also supported in another study by Cross et al. (1994).

Appropriate nutrition intervention not only increased height for weight for these children, but also makes a significant difference in the alertness of children with disabilities, especially children with feeding tubes. Caution should be given due to the small sample size. More research is needed to support this finding. Findings of this study, indicate that gastrostomy tube fed children were fed more often and showed increased levels of alertness than children who were fed orally. One explanation of this difference is that children who are fed orally may have more behavior problems associated with feeding. If you can not get the child to eat, what good is a well developed nutritional intervention plan? This study indicates that not addressing behavioral problems associated with feeding is detrimental to meeting the nutritional needs of children with disabilities. Including other professionals such as behavior interventionists or psychologists in the development of nutrition intervention plans would be an asset in addressing the needs of children with disabilities and feeding problems. A variety of
methods of intervention are available in addressing behavioral problems associated with feeding (Luiselli, 1994). Integrating concepts from a variety of disciplines is challenging for professionals in the area of disabilities. More training is needed to assist multidisciplinary teams in examining the many facets involved in meeting adequate nutrient intake.

As outlined in figure 1, there needs to be an integrated approach in addressing adequate nutrient intake for children with disabilities and feeding problems. This study supports the need for an integrated approach. How to integrate this model into training for professionals in the field of disabilities is the next challenging step. Further research of particular intervention strategies that integrates all three elements as outlined in figure 1 need to be explored.

The nutrition problems for children with disabilities can have a negative impact on the family's functioning (Beckman, 1982). Those children who had a greater degree of feeding difficulties (higher rating on the Feeding Scale) required significantly more time for families to feed. This can mean less time that a family has available to attend to other family needs and functions. In addition, families with children who had more feeding difficulties received less social support in addressing the feeding needs of their child. Thus, families that may need the most support, were the families who had the least support. This is an important finding for intervention with families. Those families who have children with more severe disabilities should be given opportunities to build and develop their social support network, including opportunities to connect with other families of children with disabilities.

Parents experience numerous sources of stress in caring for their child with a disability including the amount of time necessary to feed their child. Those parents who reported more time each day in feeding their child, also reported more stress. This finding is similar to one in a study by Harris and McHale (1989). They too found care giving demands such as feeding time for children with disabilities to be stressful for parents. In this study the two largest difficulties faced by families were the feeding routine and getting the child to eat enough. Addressing the needs of the family must be integrated within the child's nutrition intervention
plan. Families need support from professionals and extended family members in meeting the nutritional needs of their child. Again, there is a need for professionals to address not only the physical characteristics of the child with disabilities, but also to examine the impact of the intervention on the family system.

An interesting finding of this research is that children who were mildly disabled, have greater behavior problems associated with eating. These children with behavioral problems had parents who reported more stress. We might have expected that children with severe disabilities would have problems associated with feeding that created more stress for the family. The children with mild disabilities, who demonstrate feeding problems, are oftentimes overlooked in establishing adequate nutrient intake. This finding is helpful for professionals to be sensitive to the nutritional needs of children from all levels of disabilities.

**Summary**

Adequate nutrition is one of the most basic and necessary needs that must be addressed for a child to grow and develop. Oftentimes professionals focus on the education and health needs for children with disabilities, overlooking nutritional needs. The small sample size of this study limits generalizability and more research is needed to examine the nutritional needs of children with disabilities. But unless, we as professionals begin to recognize and understand signs of poor growth and nutrition for the child and signs of stress and lack of support for families, both children and families continue to be at risk. Professionals working in partnership with families can help ensure that these children and families not only survive, but successfully thrive.
References


Figure 1.

An Integrated Model of Feeding Associated with Disabilities
Table 1

Characteristics of Participating Children and their Families

<table>
<thead>
<tr>
<th>Variable</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Moderate</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>Severe/Profound</td>
<td>24</td>
<td>69</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
<td>49</td>
</tr>
<tr>
<td>Female</td>
<td>18</td>
<td>51</td>
</tr>
<tr>
<td><strong>Type of feeding route</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrostomy tube fed children</td>
<td>11</td>
<td>31</td>
</tr>
<tr>
<td>Non-gastrostomy tube fed children</td>
<td>24</td>
<td>69</td>
</tr>
<tr>
<td><strong>Mean of child</strong></td>
<td>84 months</td>
<td></td>
</tr>
<tr>
<td><strong>Age groups</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-3 years old</td>
<td>13</td>
<td>37</td>
</tr>
<tr>
<td>3-5 years old</td>
<td>6</td>
<td>17</td>
</tr>
<tr>
<td>6-14 years old</td>
<td>16</td>
<td>46</td>
</tr>
<tr>
<td><strong>Average # feedings per day</strong></td>
<td>6 feedings</td>
<td></td>
</tr>
<tr>
<td><strong>Average length of intervention</strong></td>
<td>16.45 months</td>
<td></td>
</tr>
</tbody>
</table>
Table 2

Characteristics of Participating Children and their Families

<table>
<thead>
<tr>
<th>Variable</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family type</strong></td>
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<td></td>
</tr>
<tr>
<td>Single parent</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>Two parent</td>
<td>23</td>
<td>66</td>
</tr>
<tr>
<td>Divorced</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td><strong>Primary caregiver</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological parent</td>
<td>28</td>
<td>80</td>
</tr>
<tr>
<td>Maternal relative</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Paternal relative</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Community program</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td><strong>Ethnic origin</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>32</td>
<td>91</td>
</tr>
<tr>
<td>Black</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td><strong>Families having other child in home</strong></td>
<td>29</td>
<td>91</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One parent employed</td>
<td>16</td>
<td>45</td>
</tr>
<tr>
<td>Both parents employed</td>
<td>11</td>
<td>32</td>
</tr>
<tr>
<td>Unemployed</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td><strong>Families receiving public assistance</strong></td>
<td>16</td>
<td>46</td>
</tr>
</tbody>
</table>
Figure 2.

Changes in The Child After Receiving Nutrition Intervention Services
Figure 3.

Categories of Parental Stress as It Relates To Meeting The Nutritional Needs of Children with Disabilities
<table>
<thead>
<tr>
<th>Feeding Scale</th>
<th>1) Adequate feeding function</th>
<th>2) Mild feeding dysfunction</th>
<th>3) Moderate feeding dysfunction (*may not have tube)</th>
<th>4) Severe-I dysfunction (*generally has tube)</th>
<th>5) Severe II dysfunction (*generally has tube)</th>
<th>6) Severe III dysfunction (*generally has tube)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Food</strong> modifications</td>
<td>-none -foods appropriate to chronological age</td>
<td>-minimal -foods appropriate to chronological age</td>
<td>-texture modification necessary -pureed or mashed (coughing or choking present otherwise)</td>
<td>-thickened or pureed -oral feedings may &quot;supplement tube feeding&quot;</td>
<td>-tube feeding -food &quot;taste&quot; only -severe coughing and choking as well as facial color changes, breathing changes may be seen with oral feeding</td>
<td>-tube feedings -no food, danger of aspiration on own secretions -if this child is orally fed, rather than tube fed, may be coughing/choking on own secretions, life threatening</td>
</tr>
<tr>
<td><strong>Liquid</strong> modifications</td>
<td>-none -liquids appropriate to chronological age</td>
<td>-no thin liquids -nectar or thickened liquids</td>
<td>-texture modification necessary -nectar or thickened only (coughing or choking present otherwise)</td>
<td>-thickened (given only with close supervision by trained person) -all liquids may be given through tube</td>
<td>-tube feeding -food &quot;taste&quot; only -severe coughing and choking as well as facial color changes, breathing changes may be seen with oral feeding</td>
<td>-tube feedings -no food, danger of aspiration on own secretions -if this child is orally fed, rather than tube fed, may be coughing/choking on own secretions, life threatening</td>
</tr>
</tbody>
</table>
Table 3.
Feeding Scale (continued)

<table>
<thead>
<tr>
<th>Proportions of meals oral/tube</th>
<th>Caregiver (training)</th>
<th>Oral-pharyngeal</th>
</tr>
</thead>
<tbody>
<tr>
<td>-oral feeding for all nutrition -serving size appropriate for physical development</td>
<td>-self feeds or can easily be fed by variety of others</td>
<td>-none</td>
</tr>
<tr>
<td>-oral feeding for at least 75 percent of nutrition -may be supplemented with tube feeding</td>
<td>-self feeds with assistance oral: fed by limited number of people who have knowledge of child -tube feeding: requires special training</td>
<td>-minimal effectively controlled by texture/position changes</td>
</tr>
<tr>
<td>-oral supplemented tube feeding -tube feeding for over 50 percent of nutrition</td>
<td>-minimal self-feeding -tube feeding: requires special training -oral: fed by limited number of people (primary caregivers) -extreme feeding behavior problems -inconsistent feeding routines -food aversions</td>
<td>-precautions for aspiration, delayed swallow, etc.</td>
</tr>
<tr>
<td>-oral not recommended -tube: 100% -oral &quot;taste&quot; only</td>
<td>-tube feeding: requires special training -oral: fed by primary caregiver only</td>
<td>-precautions for aspiration, delayed swallow, etc.</td>
</tr>
<tr>
<td>-oral not recommended -tube: 100% -no oral for taste -own secretions are dangerous</td>
<td>-tube feeding: requires special training oral: fed by primary caregiver only</td>
<td>-medical risk for oral feeding</td>
</tr>
</tbody>
</table>

1) Adequate feeding function 2) Mild feeding dysfunction 3) Moderate feeding dysfunction (*may not have tube) 4) Severe-I dysfunction (*generally has tube) 5) Severe II dysfunction (*generally has tube) 6) Severe III dysfunction (*generally has tube)
CHAPTER 2

QUALITY OF LIFE ISSUES FOR FAMILIES WHO MAKE THE DECISION TO USE A FEEDING TUBE FOR THEIR CHILD WITH DISABILITIES

A paper accepted by The Journal of The Association of Persons with Severe Handicaps

Mary Jane Brotherson (1), Mary Jane Oakland (1), Christine Secrist-Mertz (1), Ruth Litchfield (2), and Kathleen Larson (2)

Abstract

Qualitative research methods were used to study families who had made or were in the process of making the decision to use a feeding tube to meet the nutrition needs of their child with a disability. Data were gathered over a two year period through interviews with eight families. Family decision-making in the context of quality of life was examined using a theoretical family systems model. Descriptive themes and issues emerged from the data that led to a greater understanding of what families face in making this decision for their child. The data can help families and professionals work in partnership before a child becomes severely malnourished or medically compromised as a result of inadequate nutrition. The themes and issues are discussed and implications for future interventions and research are presented.

(1) Associate Professor, Associate Professor and Graduate student, respectively, Department of Human Development and Family Studies and Department of Food Science and Human Nutrition, Iowa State University. Research conducted and manuscript written by Brotherson, Oakland, and Secrist-Mertz.
(2) Litchfield and Larson provided research support.
Introduction

Nutrition is a critical factor in supporting growth, health, energy, and quality of life for children with severe disabilities. There are children with severe disabilities, however, who are at risk of malnourishment because of various feeding and nutrition problems (Brizee, Sophos, & McLaughlin, 1990; McCamman & Rues, 1990). These children may have increased nutrient and energy needs, difficulties chewing and swallowing, gastrointestinal abnormalities, drug nutrient interactions, malabsorption, or chronic constipation (Dwyer, 1988). For some of these children who are having difficulty receiving adequate nutrition, families will be faced with the decision to place a feeding tube in their child (Baer, Farnan & Mauer, 1991). The decision must be examined whether to meet nutritional needs by enteral feedings through a gastrostomy tube surgically inserted directly into the stomach or small intestine (Rempel, Colwell, & Nelson, 1988). The gastrostomy tube provides nutrients in a liquid form for children unable to take nourishment through the mouth or provides additional nourishment when oral intake is inadequate (Graff, Ault, Guess, Taylor, & Thompson, 1990). When making this decision, families must consider that for many children with severe disabilities, the gastrostomy tube will be inserted for feeding and nourishment over a prolonged period of time or permanently.

Decision-making styles in families with children with disabilities vary greatly (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993), and in families of children with severe disabilities and inadequate nutrition, decisions may be made with varying degrees of risk, uncertainty, and conflict. These decisions may be made with uncertainty about changes in quality of life, sometimes made in disagreement with professionals, and oftentimes made with fears of negative outcomes (Campbell, 1988; Hoyt, 1992; Stevenson, Gressard, Kocher & Bella, 1992). Some families of children with severe disabilities will make the decision to use a feeding tube for their child. But while there is evidence that child health and
quality of life can improve with the use of a feeding tube, parents often experience difficulties with this decision.

Enteral (tube) feedings for children with disabilities and undesirable low weight status have been shown to promote weight gain, increase alertness, and decrease irritability (Isaacs, Georgeson, Cloud, & Woodall, 1994; McClintic, Oakland, Brotherson, Secrist-Mertz & Linder, 1994; Sanders, Cox, Cannon, Blanchard, Pitcher, Paphakmis, Varealla, Maughan, 1990; Shapiro, Green, Krick, Allen & Capute, 1986). The decision to insert a gastrostomy tube, however, is not clear-cut for many families. Parents have described a variety of family issues and difficulties faced when making the decision to use a feeding tube with their child (Campbell, 1988; Hoyt, 1992; Stevenson, et al, 1992).

Stevenson, et al. (1992) surveyed 103 parents of children with feeding tubes. They found that after placing a feeding tube, 65% of the families experienced greater financial stress, and 77% experienced greater difficulty getting help from baby-sitters. These families also perceived significantly more stress with regard to time demands after getting a feeding tube than the caregivers of non-feeding tube children in a comparison group. Secrist-Mertz, Brotherson, Oakland, & Litchfield (1995) surveyed 35 parents of children with severe malnutrition and found a significant correlation between children with feeding tubes and diminished social support. Michaelis, Warzak, Stanek, & Riper (1992) surveyed 24 caregivers and found that social issues were more of a concern than medical issues for families of children with feeding tubes. The problems ranked highest were: finding a baby-sitter and planning a social life around the feeding schedule.

The literature reports both positive and negative impacts on families as a result of making this decision for their child. What is missing in the literature, however, is a knowledge of the family issues that surround this decision so that professionals can support families as they learn about, make, and successfully live with this health care decision. What issues do families face in making this decision? How can they increase the positive outcomes of this
decision for their family? How do families reconcile the fact that the literature suggests to them that their child will grow, but that the quality of their family life may suffer?

Quality of life represents the degree to which a family feels the individual and collective needs of its members are met. Each family is unique, and various factors influence how each family defines quality of life. Taylor and Bogdan (1990) assert:

Quality of life is a matter of subjective experience. That is to say, the concept has no meaning apart from what a person feels and experiences. As a corollary to the first proposition, people may experience the same circumstances differently. What enhances one person’s quality of life, may detract from another’s (pp. 34-35).

The child is a part of a family system that must, as a whole, balance the needs of all members, and respond to stress and change (Turnbull, Summers, & Brotherson, 1986). Each family system responds to stress differently and faces different family issues when making the decision to place a feeding tube in their child. Family decision-making in the context of quality of life can be examined using a theoretical family system model adapted from Turnbull, Summers, and Brotherson (1986). This model integrates family systems, family life cycle, family stress, and coping theory into a useful framework within which to study the issues of decision-making in families. This study uses an adaptation of this model to include quality of life outcomes and family perceptions as they relate to families making this decision. The study organizes the findings around the components of child and family characteristics, family perceptions, family interactions, and family life cycle, which lead to quality of life outcomes for families (see Figure 1). The two main adaptations made to this model were the inclusion of the components of family perceptions and quality of life outcomes because it is family perceptions that shape the definition of quality of life.
This study focused on families who have a child with a severe disability, and who had made or were in the process of making the decision to use a feeding tube for their child. The study used a qualitative research design to address several questions:

What are the issues families face in making a decision to place a feeding tube in their child?

What issues in quality of life do parents identify with the placement of a feeding tube?

How can professionals support families in making this health care decision for their child?

A family-centered philosophy recognizes the family as the constant in the child’s life and as the primary health care decision-maker for a child with special health care needs (Johnson, McGonigel, & Kaufman, 1989; Shelton, Jeppson, & Johnson, 1987). It is important that professionals understand the issues surrounding the decision-making process and outcomes for families who have children with disabilities and special health care needs so that they may work in partnership with families (Johnson et al., 1989; Shelton, et al. 1987).

**Method**

This qualitative research was essentially the interpretation of the meanings family members constructed from their experiences (Patton, 1990, Stainback & Stainback, 1984). It was based on the belief that the many facets of this issue for families are interrelated and systemic. This research sought an understanding of the multiple perspectives, experiences, and emotions as described in the words of the parents (Bogdan & Biklen, 1992; Goetz & LeCompte, 1984).

The qualitative methods used were particularly effective in examining the multifaceted aspects and influences in families and how they defined quality of life for themselves (Daly, 1992). Interviews with eight families (eight mothers and five fathers) allowed us to understand how families of children with severe disabilities and special health care needs gave meaning to
difficult or sensitive experiences related to feeding and nutrition for their child with severe disabilities.

Participating Families

Eight families were selected using a purposive sampling procedures to represent different points in making a decision about use of a feeding tube for their child. Three families were selected who gave a retrospective account of the decision-making process. Three other families were selected prior to the decision; of these, two were followed through the decision and one is still examining whether the decision will be necessary. Two additional families were selected immediately following the placement of the feeding tube (four weeks and two weeks).

These families were chosen because they were part of a larger nutrition intervention program in the public schools, or because the families were known to the researchers as having a child with a gastrostomy tube. All families were considering or had considered feeding tube placement, as other forms of intervention were not successful in meeting nutrition and growth needs. Other forms of intervention included food and liquid modifications for increased calories, thickened liquids, changes in textures, or precautions for aspiration. Seven of the children received nutrition intervention in the public schools, and one toddler received home-based services (Secrist-Mertz, et al., 1995).

All families had two parents or two major caregivers, however, in three of the interviews the father or male companion did not participate in the interviews. In two families, the mothers described the fathers as “not able to discuss” these issues. In the third family, the male companion did not perceive himself in the father role. All families were Caucasian and reported earning low to middle income levels ($25,000 to $60,000). Five of the families lived in homes or apartments in a Midwestern city of approximately 350,000 population; three families lived in homes in Midwestern cities of less than 50,000 population.
Eight children provided us with the opportunity to understand the issues of feeding and nutrition in their families. Six of the eight children experienced severe to profound levels of mental retardation from varying etiologies, and two children had moderate to severe levels. All of the children had significant oral motor dysfunction, predominantly due to cerebral palsy, with precautions for aspiration. Children ranged in age from 2 to 12, with the majority (six) of the children between the ages of 2-6. Table 1 provides a description of family and child demographics.

Insert Table 1 about here

Data Collection

Parents or major caregivers were interviewed in their homes at their convenience and each interview lasted approximately two hours. Two parents or caregivers were available for each interview in five families. Two interviewers (and on a few occasions three) conducted the interviews at the family’s kitchen table or living room floor. Often times, when other siblings were present the second interviewer used some of her time playing with siblings so that the parents could focus on the interview. Half of the parents were interviewed twice, and half were interviewed three times, with a fourth interview conducted with two selected families for member checks. Initial interviews were informal conversations with families, but as themes began to emerge from the data, more structured questions were asked about emerging themes.

Initial questions included:

- Describe what feeding and mealtimes have been like for you and your child.
- What has life been like for you before and/or after the feeding tube?
- What were you told about a feeding tube and how does that make you feel? OR
- What was the decision-making process like for you and your family?
- Describe how, if at all, family life has changed for you as a result of your
decision.
Describe how, if at all, professionals were supportive in this process.
More structured questions from emerging themes included:
Whose role is it in your family to feed your child, and how does that fit into your family routine?
How have your friends and other family members responded to your child's feeding tube?
Describe how the physical enjoyment of eating affected your decision?
How, if at all, is it important to you that your child enjoy meals like other family members?

After each interview, the researchers would make field notes of major impressions of issues identified in each family. Most of these field notes were made on audio tape directly following the interview so they were included as part of the transcript. In addition to the interviews and field notes, two other sources of data were collected that provided a different perspective with which to understand the experiences of families. All of the families completed a written survey on aspects of feeding routine. This survey asked families to describe, for example, who participated in feeding their child, how much time it took to prepare and feed a meal to their child, and what was stressful in meeting feeding and nutritional needs for their child. For five of the families, videotapes were made of the child and parent or parents. These videotapes included a time segment of the child playing or being fed and a time segment of interviewing with the parent or parents.

All families, regardless of number of parents or caregivers participating in the interviews, were paid $100 for their time. Completion of the interviews with parents covered a two year period, with most individual families participating over a 9 to 12 month period. The two families involved in member checks were involved for two years.
Data Analysis

Data analysis was continuous so that an emergent design could enable researchers to respond analytically to what they heard from subsequent parent interviews. Interviews were transcribed and content analyzed simultaneously as the issues and themes emerged in the lives of the families (Johnson & Montagne, 1992; Tesch, 1990). Issues of credibility and dependability of data were addressed to ensure rigor of design (Brotherson & Goldstein, 1992; Guba, 1981). Credibility addressed the issue of congruence between the constructed realities of the families and those realities represented by the research team and attributed to the families. Dependability addressed the issue of maintaining research stability and consistency while allowing for an emergent design. Several techniques were used to assure credibility and dependability.

**Triangulation of data.** Triangulation involved bringing more than one source of data and more than one researcher’s perspective to bear on understanding the issues and perspectives of families. Individual interviews with parents, personal writings of two parents, survey data collected on feeding routine and stress and member check interviews were used to corroborate data. The perspectives of six researchers and assistant researchers were involved in conducting interviews and analyzing the data.

**Group debriefing.** During on-going discussions with research colleagues, collective ideas and perceptions of both data and interpretations were discussed and probed to identify emerging themes and issues (Glesne & Peshkin, 1992). The research team met weekly over a two year period to organize and discuss on-going data collection. The videotapes of families helped the researchers to see and know the families thus enhancing data review and interpretation. On-going data collection, changing interview questions, and emerging themes and issues were recorded so that the study could be an integrated and on-going process.

**Member checks.** This is a recursive process of taking information gathered and interpretations made back to parents for discussion in a process that draws the respondents into
checking the credibility of findings. Parents were asked about the issues that were raised in other interviews (e.g., other families have said XX, is this an issue for your family?). In addition, a final process was used to take the organized themes and issues back to families for their reflection and feedback (e.g., does this decision-making summary reflect what you said to us? do you have any additional comments?). Member checks resulted in clarifying several concepts into more family-centered perspectives and family-friendly terms.

Following established qualitative analysis procedures (Goetz & LeCompte, 1984; Patton, 1990; Taylor & Bogdan, 1984), we began by reading and rereading the transcripts and field notes to identify major themes or issues for families. Five levels of analysis were then performed.

A first researcher read transcripts and recorded major themes and issues in “synthesis statements” in the margins of transcripts.

A second and third researcher read the transcript and validated the original “synthesis statements”. These researchers could also add issues or identify additional themes. If there were any points of disagreement they were discussed with the research team at group debriefings until consensus was reached.

The “synthesis statements” were used to identify the major themes or issues for understanding this health care decision-making in families with a family systems framework. Some of the initial themes that emerged were general and broad, for example: social support, health, intervention, mealtime, outcome, professionals, stress, and quality of life.

In an on-going process, interviews were conducted, reread, and compared to the initial themes and issues observed so that continuous feedback could divide, merge, or create new themes in a “constant comparative method” (Glaser & Strauss, 1967). Themes and issues were organized and integrated
within the five components of the family systems framework.

Last, after reaching a point of saturation (no new themes or issues emerging), the themes and issues of decision-making were taken back to two selected families for member checks.

Findings

Analysis of family interviews identified major themes and issues of decision-making within a family systems framework. Five major categories (child and family characteristics and resources, family perceptions, family interactions, family life cycle, and family quality of life outcomes) were used to organize the data (see figure 1). The themes and issues related to each of these five major categories are discussed with examples that demonstrate how different families made decisions to respond to the nutritional needs of their child.

Child and Family Characteristics and Resources

This category emphasizes how the uniqueness and diversity of families can influence perceptions and decision-making. Family resources, membership characteristics, and personal experiences affect a family's response to disability and in turn shape their perceptions and interactions. Four major issues that influenced family decision-making were identified in this category.

Nutritional/health status of the child. The families in this study did not perceive their child as severely undernourished or nutritionally compromised in the initial stages of decision-making. Each child had extensive oral-motor problems and compromised respiratory status; all had cerebral palsy. Six children had extremely undesirable weight status at the time the families decided or were considering placement of a feeding tube in their child.

In the remaining two families, the feeding tube was inserted in the child during other surgical procedures. For these families the decision was whether to continue to feed their child with the feeding tube or take it out following surgery. One family removed it and later made
the decision to reinsert the tube. The other family chose to leave the feeding tube in place following surgery.

**Information.** Seven families made the decision to place a feeding tube; the eighth family is still considering it. Initially they did not have expectations for their child to weigh more or had been told by professionals that their child’s weight was adequate. Several families described working with professionals (e.g., occupational therapists, special educators, speech pathologist, nurses) who focused on interventions and management of care but did not provide information or discuss malnutrition with them. The professionals may have been unaware that these children were malnourished or assumed that nutrition was being addressed by other services.

The levels and types of information families had received influenced how accurate their perceptions of adequate nutrition were for their child, ultimately influencing their decisions. Parents were often given little information, conflicting information, or no information from professionals, all of which made the process more difficult. For example, one father had been told by the therapist working with his child that “the feeding tube will close the door on development of vocalizations.” Two of the families thought their child would require an intravenous bag hanging down at mealtimes and three of the families thought their child would never be able to taste food again. Several families said it had been difficult to find the resource people who would listen and provide information.

Parents who had been feeding their child with a tube for two years still lacked information to appropriately provide a tube feeding. The parents were laying their child flat on the floor, pouring refrigerated milk and baby food into the tube, and blowing into the tube when it became clogged. When given adequate information this family began feeding their child with more appropriate positioning, formula, and technique, as a result, the child’s vomiting decreased and she began to gain weight.
Only one family of the eight studied was given information by professionals to contact other parents who had gone through similar experiences. Seven families, however, stated they wished they had been given more opportunities to talk with other families facing similar issues.

**Social supports.** The eight families in this study had various levels of social support available to them that impacted their quality of life before or after their child received a feeding tube. All eight families reported some support from extended family and friends in feeding their child prior to receiving the feeding tube. After the feeding tube, however, five families expressed stress in losing some of this support. This finding was supported both through the interviews with the families and the survey data collected on feeding routine and stress.

Families were asked to rate on a 10 point scale how helpful they perceived their family and friends in feeding their child before and after the feeding tube. Extended family members in the past had helped with the feeding were intimidated and unsure about feeding a child through a tube. One family described being able to take their first vacation in six years after finally finding a respite care provider who could feed and care for their child.

Five families experiencing loss of social support had been told that a feeding tube should make feeding and mealtimes with their child easier, by decreasing aspiration, shortening feeding time, and utilizing commercial formula. The reality for these parents, however, was that one aspect of feeding became more difficult, fewer people could or would help feed. This finding was supported both by the interviews and the survey data from families. This stress was keenly felt by mothers who worked outside the home. These mothers had major responsibility for feeding their child, or felt it was their role as a mother to feed their child.

**Parent knowledge and experience.** Each of the families came to the decision-making process with different levels of experience and knowledge of disability. Two issues significantly influenced decision-making: past experience with disabilities and life expectancy of their child. Five of the families had past experience with disability through an extended family member or occupational activities. As one of these parents stated, “I already knew some
of the people I need to go to for help.” If parents had more experience with disability they seemed more willing to use a feeding tube. Two families had expected their child to die; in one family this precipitated the decision to get a feeding tube and in the other it created an attitude of “why put her through this.”

**Family Perceptions**

Cognitive perceptions can influence the adaptation of families to the stressful experiences of living with a child with chronic illness or disability (McCubbin & Patterson, 1982; McCubbin & Patterson, 1983). These cognitive perceptions may be related to the significance of the disability, comparisons to other children, spiritual meaning attributed to the disability, or family expectations (Turnbull, et al., 1993). These perceptions can be influenced by the characteristics, resources, and interaction of the family, and change over the life course of family members. In this study, we examined how the need to address feeding and nutrition problems was influenced by the family’s beliefs and perceptions. In this category, there were four perceptions identified that were particularly relevant to making the decision of feeding tube placement in their child. Family perceptions were the major factors that caused some families to resist or delay making the decision to use a feeding tube with their child.

**Enjoyment of eating.** Four families described the importance of eating and the mealtime experience to the quality of their child’s life. Therefore, by placing a feeding tube in their child, they felt they would be taking away something their child and family enjoyed. In these families, mealtimes were a large part of their interaction time with their child. One mother stated that, “I am not giving up feeding her. She enjoys it. I can tell when she likes a flavor...I know she enjoys eating. And that’s important to her.” Another mother said, “She likes sweets...I will settle for this tube as long as she can still eat cupcakes and have her candy once in a while.” A father shared retrospectively, “My biggest concern was how much he enjoyed eating. Much of his awareness and enjoyment centered around eating. We were concerned about all that he would be missing out on in making the decision to stop feeding
him.” In personal writing shared by this father, he stated that holding, intimacy, and stimulation were also an important part of mealtime interactions for him and his son.

Maintain normalcy. Five families described their belief that maintaining a normal life for their child did not include a feeding tube. This belief was one of the most difficult aspects of making this decision for these families. As one mother stated: “My daughter can’t walk, talk, sit-up, she can’t do anything normal. The closest thing I have to normal with her is feeding her and I don’t want to take that away.” A father shared that the guiding principle of providing care for their son was to “provide him with the most normal life possible, and not feeding him was not normal.”

One family was on the other side of this issue; normalcy for this family meant getting a feeding tube. The father shared, “the amount of trouble it was to feed her was abnormal.” The feeding experience with their child was so difficult and stressful, that getting a feeding tube was “getting back to normal for the family.”

Visibility of disability. A related aspect of normalcy for families was the increased visibility of their child’s disability as a result of having a “tube hanging out of this little kid’s body.” The visibility of a health problem was qualitatively different than the visibility of disability for some families. These parents seemed to feel that the device made their child “less human” or “subhuman”.

Some of this concern also related to the lack of information as seen in the two families who initially thought the child would carry an intravenous bottle hanging overhead. Four families discussed this issue, and in two of the families the children were extremely underweight. It is important to understand that some families perceived the tube as a greater visible sign of disability than the extremely thin and low body weight of their child. Some families had been told by professionals to expect a very thin and low weight child; it was part of the disability. For these families the feeding tube was a dramatic and highly visible reality of disability, while the progression to malnutrition was a slower, more subtle change.
Provide nurturance. “Love is preparing and giving food, it’s hard to think of a feeding tube as the same act of love.” This parent and others viewed a feeding tube as sacrificing a special nurturance and belonging they offered their child. This attitude was observed in their use of language. Five families talked about getting a feeding tube as “when we stopped feeding our child.”

It is interesting to note when these children were receiving the most physical nourishment they had received in years, parents perceived this as losing social and emotional nourishment. “When she’s hooked up to the drip feeding you don’t have as much stimulation. So trying to fit as much nutrition as she needs into a day without decreasing her stimulation is hard.” This mother also shared that at school it is difficult for teachers to involve her daughter in community activities and also have enough time to complete her feedings.

Family Interactions

Family interactions are based on the premise that behavior among family members is interrelated so that changes in one individual affects change throughout the entire family. Each member is influenced by every other member and by the system as a whole (Turnbull, et al., 1986). Issues of family perceptions were the most significant concerns that delayed or caused a family to struggle with the decision. But the issues of family perceptions were set aside or set in abeyance when families had to attend to practical issues. In some families, it was the pragmatic issue of family interactions that was the most decisive. This study identified four major issues of interaction that played a significant role in family decision-making.

Decision-making style. Families varied in whether they viewed the decision as “their decision” or a decision of the medical professionals. Families in our study were on both ends of the continuum, some felt it was totally their decision and others felt more dependent on medical professionals. Overall, families tended to want more professional support when their child’s condition was acute, and greater social support when their child’s condition was chronic.
In six families, the decision was directly an issue of "whether or not to have a feeding tube placed." In one family, the decision focused more on "how to get support to accomplish it," and in the eighth family the decision focused on "should we take the feeding tube out." The decision for all of these families was a decision that involved more than health issues. As one father stated:

> These are the things I would like to have had considered, not just the medical point of view, but his enjoyment of eating and his participation in something very normal. His appearance to people and other children that he doesn't look weird, how it would restrict other people taking care of him, and how this would put more restrictions on us getting help with his care are also considerations.

Families varied in who was involved in decision-making. Four families had decision-making styles that involved both parents. Three involved only the mother or in one case the other and her sister. In one family the decision was made by the father, even though mother was the primary caregiver.

**Turning points.** As family interactions changed over time, certain life cycle events influenced families to consider or reconsider the decision to place a feeding tube in their child. In one family, it was the birth of a new baby and the need to balance parental time between two children. In another family, it was the transition of the oldest sibling into high school and dating activities. The teenage daughter had played a significant role in feeding and when her role changed, the mother reconsidered the decision to place a feeding tube.

For two families, the turning points were connected with medical procedures that provided visual information to the families. Fluoroscopy finally led one family to make the decision to place the tube as they watched their daughter's lungs fill with fluid. The second family, observed nurses unsuccessfully trying to feed their son during a hospital stay. At that
time, the parents realized how risky oral feeding was and that they could not continue as the
sole feeders for their son.

Time and convenience. Families indicated in survey data that before the decision to
place a feeding tube the amount of time needed to feed their child ranged from one and a half to
five hours a day, and feeding times ranged from three to 12 times per day. For the seven
families who made the decision to place a feeding tube in their child, the time required for
feeding diminished after the tube was inserted. In one family, however, maintaining a routine
of regular tube feedings was difficult and sometimes chaotic. They discussed several times the
experience of finding themselves away from home without the tubing to feed their child
through her button gastrostomy tube. This was a child who could swallow and eat orally but
the family chose to leave the feeding tube in for convenience. They believed they would be
better able to feed her through a tube than to struggle with feeding her orally for long periods of
time. Their daughter was orally defensive and "why make her life miserable if she isn't going
to live very long?"

The mother whose decision to place a feeding tube was precipitated by the birth of a
new baby expressed that "it wouldn't have worked to spend an hour for each feeding." For
another mother reducing the amount of time required to feed her daughter was related to loving
her child. She stated, "As a mother I needed to love her. If I would have had to keep feeding
her I would have been too frustrated to love her." For this mother and several others, the
feeding tube also provided a more convenient means of hydration and administering
medications for their children.

Impact on family roles. All families had either two parents or two caregivers in the
home. In three families, the feeding and child care were shared between caregivers. In five
families, it was the mother's main role to feed the child and after a feeding tube was inserted
this became an even greater role for her. One mother stated, "My husband cannot feed her at
all."
Three of the mothers not only saw this as their role but also felt that they were not fulfilling their role as a mother if they were not orally feeding their child. One mother expressed this as:

I feel like we put her in kind of a normal bracket, like she is a normal child. We treat her like a normal child. The tube feeding...it makes me feel like I have let her down. But that’s the way I feel, that I am not doing my part as a mother and I am letting her down and that’s my last resort.

Family Life Cycle

Family life cycle development is the dynamic element of a family systems framework (Carter & McGoldrick, 1980). As families move through time, normative and non-normative changes alter their interactions and quality of life. The issues identified in this category assist us to understand how normative and non-normative life cycle changes are influenced by feeding and nutrition problems. Two major issues identified in this category help us to understand families within a life span context.

Malnutrition occurs over time. Five children were undernourished when the feeding tube was inserted as their weight for height was below the fifth percentile on standard growth charts. For these families, malnutrition was something that happened, almost unnoticed, over a period of time. Many of these children had been born small for gestational age or spent time in neonatal intensive care units as a result of prematurity. Many of these parents had seen their children in precarious medical conditions or had been told by medical professionals to expect growth retardation or “stunted growth” as a result of the disability. Lowered expectations resulted in some parents not understanding that inadequate food intake compromises growth, immune status, and developmental skills.

Suspended expectations. All of these families experienced suspended expectations of normal life cycle changes. All eight of these children were totally dependent on their families for care, or in the case of two families, on the family and home health aide. Suspended
expectations were tied to the issue of malnutrition over time as parents did not perceive lack of physical growth or they had been told to expect stunted physical growth. Several families perceived the feeding tube as less normal than a child who was abnormally small and too weak to interact with the environment or people in it.

**Family Quality of Life Outcomes**

Family quality of life outcomes are the products of family perceptions, interactions and responses to change. These quality of life outcomes represent the family’s subjective level of satisfaction with the degree to which they meet the individual and collective needs of the family in a variety of domains (Turnbull, et al., 1986). Nutrition and physical health are major domains of family functioning in which each family member has needs to be met. How a family meets these needs varies depending on the value and priority the family attaches to this function. Four major issues of quality of life were identified in families after placement of the feeding tube. These included both positive and negative outcomes for some families, but overall the families experienced positive quality of life outcomes as a result of their decision to place a feeding tube in their child.

**Changes in health and nutritional status.** Seven families experienced positive child changes as a result of the feeding tube. The families described their child as: gaining weight, healthier, brighter eyes, greater strength, and ability to attend school more regularly after the feeding tube was placed. One family is still weighing the decision and has not yet placed a tube in their child. Their child has significant oral-motor difficulties and the decision may still need to be made; however, this child had moderate weight gain in the last six months after receiving nutrition intervention services to increase oral intake.

**Alertness and increased interaction.** Six families described greater alertness and interaction as a result of the feeding tube. Increased child interaction led to increased parent interaction. Families talked about their children: being happier, playing more, interacting more, having enhanced environmental awareness, playing more with siblings, being calmer, and
smiling. The smiles of the children were their way of nourishing the family, their contribution to the family. As one mother shared, “it is as though he came back to life.”

**Costs: human and financial.** Some, but not all families, had insurance that would cover the high cost of formula feedings. Five families paid for part or all of the formula expense. The recommended daily allowance of Pediasure (Ross Laboratory) for a child between the age of one and six is approximately four, eight ounce cans daily. As the cost of $2.16 a can, that is approximately $255 a month for formula. This does not include the expense of medical supplies. Thus, for those who did not have expenses reimbursed, a feeding tube could be costly. One family chose to put baby food down the feeding tube of their daughter because it was convenient and less expensive, even though it was not providing their child with adequate nutrition.

The human costs to families included greater stigma and isolation as a result of what they perceived as a “more visible” disability. This was not true for all the families; the issues of stigma and isolation were tied to family perceptions of disability. Many of these families did not go out into the community very often, but the feeding tube made it even more difficult. An additional cost for some families was the diminished role of their social support network which was discussed earlier.

Two families who had home health aides, experienced a loss of family privacy as a result of allowing numerous professionals into their homes and the continual need to disclose financial information. Both of these families are concerned about changes in health care and insurance which may affect Medicaid benefits. One of these families knew their insurance would cover expenses if their child received a feeding tube and this knowledge helped them to make the decision to get a feeding tube.

**Unforeseen benefits.** Families described many unforeseen benefits as a result of placing the feeding tube in their child. Their child’s changes affected them in different ways. One mother described a much greater enjoyment of her child as a result of the decision to place
a feeding tube. For two families, the placement of a feeding tube allowed them to receive home health care, a service that created some family intrusion, but also relieved the family of many physical care demands. Three families described greatly reduced stress levels.

One father stated, “the unforeseen benefits were amazing to us. In a week he was healthier and happier. It was a big surprise that he gained so many things. We were able to shift our focus from just survival to other things.” Three families described how much of their time and interactions with their child had centered around feeding, and how a new world of interactions was discovered.

Discussion

This study gives professionals an opportunity to understand feeding and nutrition issues within the context of the family system. Thus, professionals are offered greater information to identify, interpret, and explore individual family values and issues. Professionals and families are given a stronger foundation to work in partnership before a child becomes severely malnourished or medically compromised as a result of inadequate nutrition.

These interviews provided information to understand the general phenomenon of this decision in families at different points of decision making. Researchers can compare the findings of this study in other contexts to understand the phenomena across contexts and time. In the following paragraphs or sections, the findings from the perspectives of families, professionals working with families, and researchers, are discussed.

A Balance of Family Needs

This can be a difficult decision for a family. They may be confronted with the balance between the issues of quality of life for the parents or family as a whole, and issues of quality of life for the child. A family must decide how to balance the child’s and family’s need for normalcy with the child’s need for health and nutrition. A family’s decision could compromise the nutritional health status of their child as well as quality of life for the child.
The decision to place a feeding tube in their child may seem contradictory to a family. A feeding tube should make feeding easier, but it may make it more difficult if the support they have to feed their child diminishes or financial costs increase. This finding is consistent with earlier research that identified financial stress and lack of social support in parents of children with feeding tubes (Michaelis et al., 1992; Stevenson et al., 1992). A feeding tube should mean that their child gets adequate nutrient intake, but if the social support diminishes, nutrient intake may also diminish. A feeding tube should improve their child’s health and immune system, but if a child gives up enjoyment of eating and becomes more isolated, the child and the family may experience diminished quality of life. As these results indicate, this decision is tied to a number of family issues.

Figure 1 highlights some of the major themes and issues of decision making according to each family’s definition of quality of life. Quality of life improved overall for most of the children and families in this study. Consistent with previous research (Isaacs et al., 1994; McClintic et al., 1994; Saunders et al., 1990), these children gained weight, were more alert, and interacted more with their family and environments as a result of the feeding tube. For some the decision was a tradeoff of one set of problems for a new set of problems. For most of the families, however, the improved interactions and smiles of their children made the decision “the right decision for their family.”

These families could identify positive outcomes for their child and family as a result of the decision to place a feeding tube in their child. These findings are in contrast with the predominantly negative findings of greater stress and problems for families that is evident in the research (Michaelis et al., 1992; Secrist-Mertz et al., 1995; Stevenson, et al., 1992). For these families, the balance of family needs may not have been easy, but it was not always negative.
Intervention Directions

Professionals and families must learn from each other to work as a collaborative team in making health care decisions. Team members can share nutrition information in a manner that is correct and not conflicting, and that ensures the nutritional needs of the child are identified and coordinated among service providers. Educators and related service providers often use mealtime to provide practice on attaining functional skills such as self-feeding. For some children, however, a focus on independent eating could result in inadequate nutrition and growth (Ault, Guy, Rues, Noto, & Guess, 1994). The Individuals with Disabilities Education Act (IDEA) includes nutrition as a related service. Team members need the knowledge and the skills to work with families to recognize signs of poor nutrition and growth in children.

Professionals can also assist families in identifying or exploring issues of quality of life for their family. Some families may need emotional support to make this decision. For these families, professionals should be aware of signs that a family might be struggling: concern about visibility of disability, need to nurture through feeding by mouth, loss of social support, or greater isolation. Families in this study suggest to us that decisions should be discussed in the family’s language and their context, rather than presented as a medical procedure, an enteral tube. Focus should be on nourishing the child, not tube feeding. Nourishing and nurturing can sound and feel similar.

Professionals can explore with families how enjoyment can be increased for themselves and their child, rather than decreased by this decision. Extended family members and friends may wish for information on feeding a child with a tube so that they can be supportive. Families can be faced with many issues through this decision, some families will experience difficulties and others will not. Professionals need to have a sensitive understanding of the issues involved so they can support families.
Implications for Professionals

The right to grow is a basic need of children with disabilities. The well-nourished child is more able to interact with people and things in the environment, take advantage of social and learning experiences, and participate in community life. The findings of this study pose some challenges. Future research should identify and examine ways to effectively meet the information needs and social support needs of families who are making this health care decision. Future research should also examine ways to successfully respond to the stress primary caregivers experience when making the decision to place a feeding tube in their child.

A difficult ethical question raised by this research is to what degree should children become nutritionally compromised before parents and professionals intervene with the placement of a feeding tube. These children may be falling through the cracks of the education and health systems. The Individual with Disabilities Education Act (IDEA), Part H, identifies nutritionists as qualified providers of services; it is important that children are screened for nutrition problems and that nutritionists are included on the early intervention team. A goal of intervention must be to enable families to make health care decisions in a manner that improves the quality of life for their child and family.

References


Tesch, R. (1990). *Qualitative research: Analysis types and software tools*. New
York: Falmer Press.


Figure 1.

Major Themes and Issues for Family Decision Making and Feeding Tubes
Table 1

**Characteristics of Participating Families**

<table>
<thead>
<tr>
<th>Family</th>
<th>Child's Description</th>
<th>Family Structure</th>
<th>Major Caregivers</th>
<th>Primary Source of Income</th>
<th>Educational Level of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Eight year old male with CP and MR</td>
<td>married; 2 parents</td>
<td>2 parents; home health aide</td>
<td>both parents</td>
<td>both graduate degrees</td>
</tr>
<tr>
<td>02</td>
<td>Six year old female with CP and MR</td>
<td>married; 2 parents; 1 sibling</td>
<td>2 parents; home health aide</td>
<td>mother-full-time father-grad student</td>
<td>both graduate degrees</td>
</tr>
<tr>
<td>03</td>
<td>Twelve year old female with CP and MR</td>
<td>married; 2 parents; 1 sibling</td>
<td>mother</td>
<td>father-full-time mother-part-time</td>
<td>both high school graduates</td>
</tr>
<tr>
<td>04</td>
<td>Five year old female with CP and MR</td>
<td>married; 2 parents; 1 sibling</td>
<td>mother (dad &amp; grandma help)</td>
<td>both parents</td>
<td>both high school graduates</td>
</tr>
<tr>
<td>05</td>
<td>Three year old male with CP and MR</td>
<td>single-mother, significant other; 1 sibling</td>
<td>mother</td>
<td>government support</td>
<td>high school graduate</td>
</tr>
<tr>
<td>06</td>
<td>Four year old female with CP &amp; MR</td>
<td>married; 2 parents; 1 sibling</td>
<td>mother</td>
<td>both parents</td>
<td>father-high school; mother-high school plus</td>
</tr>
<tr>
<td>07</td>
<td>Two year old female with CP and MR</td>
<td>married; 2 parents; 2 siblings</td>
<td>2 parents share</td>
<td>both parents</td>
<td>both graduate degrees</td>
</tr>
<tr>
<td>08</td>
<td>Four year old female with CP and MR</td>
<td>married; 2 parents; 2 siblings</td>
<td>mother</td>
<td>father-full time mother-part-time</td>
<td>father-high school plus; mother-high school</td>
</tr>
</tbody>
</table>

Note: CP stands for Cerebral Palsy, MR stands for Mental Retardation.
GENERAL CONCLUSIONS

Adequate nutrition is one of the most basic and necessary needs that must be addressed for a child to grow and develop (Cloud, 1993). Children with severe disabilities have many of the same basic requirements as other children for nutrient intake and some may even have increased requirements (Ault et al., 1994). Risk factors, however, associated with genetic and or metabolic disorders, birth defects, infections, perinatal drug exposure, or handicapping condition, impair the nutritional status of 10% to 25% of the pediatric population (Baer, Farnan, & Mauer, 1991). Nutritional intervention is viewed as an essential health service to enable children with disabilities and chronic illnesses to attain maximum potential and quality of life.

Nutritional intervention is also viewed as essential to help families respond to and meet the feeding and nutritional needs of their child. Children with disabilities and feeding problems continue to be at risk because professionals in the field of disabilities lack the knowledge in understanding and recognizing signs of poor growth and malnutrition for these children.

Professional from the educational field are not the only ones who are failing to recognize signs of poor growth and malnutrition. Medical personnel are also not aware and sensitive to the needs of these children. As discussed in the second paper, families had been told by professionals that their child's weight was adequate, even though the child was below the 5th percentile for weight for height. Families themselves indicated that they did not perceive their child as severely malnourished or nutritionally compromised. This ignorance by professionals and families of children with disabilities and feeding problems, continues to put these children at risk for health problems, learning deficits, and even death (Ault et al., 1994).

One avenue for meeting the needs of children with disabilities and feeding problems, is Public Law 102-119, the reauthorization of the Individuals with Disabilities Education Act (IDEA). Part H, of IDEA, includes nutrition as one of ten disciplines on the teams providing early intervention services to young children with disabilities and their families. Both of the studies in this dissertation, support the role of the dietitian as an important member of the
nutrition intervention team. Providing school-based nutrition services is needed to better assess and develop intervention plans.

Having nutritional services available to children with disabilities and their families has shown to have positive effects (Secrist-Mertz et al., 1995; Cross et al., 1994). In a study by Secrist-Mertz (1995), weight gain and increased alertness were two of the outcomes of school-based nutrition services. These findings support the need for school-based nutrition services.

Dietitians can serve children and families with disabilities and feeding problems in a variety of ways. Dietitians can work collaboratively with other disciplines in addressing feeding problems and can also provide accurate information to parents or caregivers. Many families faced with the decision to place a gastrostomy tube in their child, lacked information. Parents were often given little information, conflicting information, or no information from professionals, all of which made the process more difficult (Brotherson et al., 1995). Many families who are faced with the decision to place a gastrostomy tube in their child did not know where to turn to get help or assistant with this decision. School-based nutritional services could be one way to connect families together who had similar experiences with having a child with disabilities and feeding problems.

There needs to be an integrated approach in addressing adequate nutrient intake for children with disabilities and feeding problems. Integrating this model into training professionals in the field of disabilities is the next challenging step. This is an area for further research and development. Families and professionals must learn from each other to work as a collaborative team in making health care decisions. Team members can share nutrition information in a manner that is correct and not conflicting, and that ensures that nutritional needs of the child are identified and coordinated among service providers. These teams of professionals would benefit from having the knowledge of an integrated approach in addressing the nutritional needs of children with disabilities and their families.
There are many facets that compound the feeding process. Intervention plans need to be designed not only based on the physical characteristics of the child with disabilities, but also must take into account other issues as well. Children with mild disabilities were often overlooked in addressing the behavioral issues of children as it relates to eating. Professionals need to be sensitive to the nutritional needs of children from all levels of disabilities.

It would be beneficial to include other professionals as part of the multidisciplinary team in addressing the nutritional needs of these children. Other disciplines such as psychology and family therapy could bring new ideas and directions in providing services to children with disabilities and nutritional problems.

**Implications for Family Therapists**

The reauthorization of the Individuals with Disabilities Education Act includes marriage and family therapist as providers of services for children and families with disabilities. The belief that a team approach is important and that families are essential members of the team is a vital part of the law (Joanning et al., 1994). Family therapists can assist families in becoming active team members and work with families in a variety of ways.

The two studies included in this dissertation support the need to use an integrated approach in meeting the nutritional needs of children with disabilities and their families. Taking an integrated approach helps facilitate the idea of looking at all aspects of feeding within the context of the family. Families faced with the decision to place a gastrotomy tube and caring for a child with a gastrostomy tube experience stress and a lack of social support. Family therapists would be able to assist these families in finding solutions to address the issues of stress. Families are also faced with challenges in redefining their role. Especially mothers, are greatly effected by the placement of a gastrostomy tube. In the second study, several of the mothers in the study felt that they were not fulfilling their role as a mother if they were not orally feeding their child. Family therapists could assist family members in redefining their role as it relates to changes the family is experiencing.
Emotional issues surrounding the idea that their child may die due to malnutrition is something families having children with disabilities and nutritional problems may face. Family therapists can help families discuss and deal with these issues. Family therapists can also assist other professionals in dealing with their own issues of grief and sadness in working with medically fragile children.

It is imperative that professionals begin to recognize signs of poor growth and nutrition for children with disabilities and focus on signs of stress and lack of support for families. Without this awareness children with disabilities and their families will continue to be at risk. Adding the service of nutritionists and family therapists to the law may help facilitate an increased awareness and an avenue to better serve children with disabilities and their families.

References


APPENDIX
PARENT INFORMATION ON NUTRITIONAL PROGRAM

Code number ____________ Today's Date ____________

Feeding Information

How long does it take to prepare a meal (puree, grind, mash)?____________________

How long does it take for you to feed your child one meal?____________________

Is your child fed separately from other family members? _____ Yes _____ No

How many meals a day do you feed to your child?____________________

How many snacks a day do you feed to your child?____________________

How much time per day (total) is spent feeding your child?____________________

List the people in your home who are involved in feeding your child:

<table>
<thead>
<tr>
<th>Name</th>
<th>Amount of time/day</th>
</tr>
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</table>

How well do you feel the school has successfully met the nutritional needs of your child? (circle a number)

0 2 3 4 5 6 7 8 9 10
not well very well

How stressed are you in meeting the nutritional needs of your child? (circle one)

0 2 3 4 5 6 7 8 9 10
no stress most stress

How helpful are relatives and friends to you in meeting the nutritional needs of your child? (circle one)

0 2 3 4 5 6 7 8 9 10
no help very helpful
How would you rate your child's overall alertness and responsiveness since beginning the nutrition program? (circle one)

0 2 3 4 5 6 7 8 9 10
not alert/responsive very alert/responsive

What has been most stressful for you in meeting the feeding and nutritional needs for your child?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Who, if anyone, has been most supportive to you in meeting the nutritional needs of your child?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Describe what changes you have seen in your child since he or she began the nutrition program.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Any Other Comments

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you for giving us this information
Your support will help us to improve programs

Please return in enclosed envelope