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PARENTAL PERCEPTIONS OF FEEDING YOUNG CHILDREN WITH DEVELOPMENTAL AND EATING PROBLEMS

John Leonard Pagano, Ph.D.

University of Connecticut, 2000

Feeding interventions with young children who have developmental and eating problems frequently emphasize the mechanics of feeding, giving less attention to parent's feeding experiences. Based on family systems and social exchange theories, this study investigated parents' experiences of feeding their child with developmental and eating problems. Parents' perceptions of feeding difficulties, feeding rewards, overall feeding satisfaction, parenting stress, and the impact of feeding intervention were assessed. The study focused on the relevance of family systems and exchange theories to the study of parents' feeding perceptions, and the implications of parents' feeding perceptions for family-centered feeding assessment and intervention.

Thirty-one parents of toddlers and preschoolers with developmental and eating problems were interviewed and filled out self-report questionnaires related to feeding. All of the families were current or former participants in Birth-to-Three programs, most from Connecticut. Parents described their perceptions of feeding in response to open-ended and scale scored questions. Parenting Stress was assessed using the Parenting Stress Index/Short Form, and demographic and medical information was collected.

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The primary feeding difficulties reported by parents, such as their child's resistance to eating, are described. Parents' rewarding feeding experiences, such as when their child progressed in his or her eating ability, also are described. Parents' overall satisfaction with feeding reflected considerable individual differences in parent responses, but approximately half of the parents ranked feeding as their least favorite child care task.

Parents had very high parenting stress levels, half with scores indicating clinically significant levels of stress. A significant negative correlation was found between parenting stress and ratings of overall feeding satisfaction. Parents reported feeding intervention had either a positive (42%), both positive and negative (23%), negative (11%), or no impact (11%).

This study supported the use of the family systems and exchange theories for understanding parents' feeding perceptions. Application of the results to family-centered feeding intervention and future research are discussed. Implications include the importance of assisting parents through specific feeding strategies and social support, promoting parents' rewarding feeding experiences, and considering parents' individual perceptions and needs in determining the best ways to include them in feeding intervention efforts.

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PARENTAL PERCEPTIONS OF FEEDING YOUNG CHILDREN WITH DEVELOPMENTAL AND EATING PROBLEMS

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A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

at the

University of Connecticut

2000

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APPROVAL PAGE

Doctor of Philosophy Dissertation

PARENTAL PERCEPTIONS OF FEEDING YOUNG CHILDREN WITH DEVELOPMENTAL AND EATING PROBLEMS

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CHAPTER I

INTRODUCTION

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General Statement of the Problem

Feeding is a major activity in the life of every young child. For young children and their parents feeding is a transactional activity most frequently carried out in the family environment. Feeding involves two major components: the mechanics of eating, and the interpersonal aspect of parent-child interactions. Parent-child interactions are influenced by the parent and child's perceptions of the feeding experience. While a good deal of information is available concerning both the mechanics of eating and parent-child interactions, less attention has been focused on parents' perceptions of feeding.

It is typical for young children to experience some feeding related problems. However, for children with special needs, feeding difficulties can be particularly problematic for the child, the parents, and the family system.

Advances in medical technology have increased the survival rate of infants with developmental problems, and a high percentage of these children have feeding difficulties. Thus, the number of toddlers and preschoolers who have developmental and feeding problems is steadily rising. There is a recognized need for feeding intervention programs to promote the growth and development of these children.

Feeding intervention is a component of many family-centered early intervention programs. However, concerns have been raised regarding the effectiveness of early intervention services in improving parents' abilities to feed their children. Family-centered early intervention providers are aware of the importance of focusing on the needs of the family, but appear to lack an adequate theoretical foundation of parenting and the family on which to base their family-centered feeding assessment and intervention services.

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Recent research suggests that many young children with mechanical eating problems also have difficulties with the interpersonal components of feeding. It appears the mechanical feeding problems and medical history of children with disabilities can contribute to difficulties in parent-child feeding interactions and parenting stress. Interpersonal aspects of feeding, including parents' feeding perceptions, have a significant effect on young children's feeding development. The physical and medical problems of the young child also have an impact on the parent and family.

Focusing only on eating mechanics and nutritional intake neglects the impact that the interpersonal components of feeding have on feeding development. Objective observations of mealtimes provide useful information about parent-child feeding interactions, but do not describe the parental perceptions influencing these interactions. The literature on children with developmental delay suggests that parent's perceptions significantly effect parent-child interactions and the development of young children with developmental problems.

Given this relationship of parents' perceptions to parent-child interactions and the developmental outcomes of young children, and the importance of feeding in the lives of young children and their parents, parent's perceptions of their young child's feeding is an important consideration for early intervention. Parents' perceptions of feeding are also an important consideration in feeding intervention because treatment is more likely to succeed if parents view the treatment as relevant and support it. For these reasons, an understanding of parents' feeding perceptions can guide the feeding treatment of young children with developmental problems.

Using the family systems and social exchange theories, this dissertation will describe parents' perceptions of feeding costs, feeding rewards, overall feeding satisfaction, feeding

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intervention, and parenting stress. The relationship between parents' perceptions of feeding and parenting stress will also be described. Implications of parents' perceptions for family-centered feeding evaluation and intervention will be discussed. The usefulness of the family systems and social exchange theories as a foundation for considering parents' perceptions of feeding young children with developmental and eating problems will also be considered.

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CHAPTER II

LITERATURE REVIEW

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Introduction

This literature review begins by describing the most common developmental and feeding problems of toddlers and preschoolers. Approaches to feeding intervention are then described, especially as they relate to family-centered early intervention and the Birth-to-Three programs. Next, parenting factors related to feeding treatment for young children with developmental problems are discussed based on the family systems and social exchange theories. Emphasis is given to research describing parents' perceptions of feeding and the relationship of parent's feeding perceptions to parenting stress and feeding intervention.

Feeding difficulties of young children with developmental problems

As a result of technological and medical advances, there is a steady increase in the percentage of young children who were born with developmental delays and disabilities. Children who in the past would have died from perinatal complications (Lachenmeyer, 1995). Children with developmental delays and disabilities have higher incidences of feeding problems (Lachenmeyer, 1995). A higher incidence of feeding problems is also seen in children born with an extremely low birth weight of less than 2.2 pounds (Connecticut Birth to Three Nutrition Task Force, 2000; Lachenmeyer, 1995).

The terminology used to describe developmental problems can be confusing for both parents and professionals. Developmental delay is a term describing children under five years old whose developmental skills are significantly below age level expectations (Levy, 1996). Developmental disabilities are problems interfering with age appropriate Functioning, including various diagnoses that can result in developmental delays (Prontnicki, 1995).

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Toddlers and preschoolers with developmental problems have more feeding and nutritional problems than typically developing children (Adams, Gordon, & Spangler, 1999; Raddish, Forsythe, & Kleinert, 1995). Ten to twenty-five percent of children with developmental disabilities have feeding or nutritional problems (Secrist-Mertz et al., 1997). Common developmental disabilities associated with an increased incidence of feeding problems include Pervasive Developmental Disorder/Autism, Cerebral Palsy, congenital metabolism disorders, congenital heart disease, cleft lip and/or palate, and Down Syndrome (Connecticut Birth to Three Nutrition Task Force, 2000; Prontnicki, 1995). Many hospital procedures commonly used in the early medical treatment of developmental disabilities and very low birth weight may also contribute to feeding problems (Delaney, 1998). These medical procedures include the use of ventilators, supplemental oxygen, tracheotomies, feeding tubes, and force feeding (Delaney, 1998; Glass & Lucas, 1990).

Pervasive Developmental Disorders are a spectrum of neurological problems that include Autism, and are characterized by social interaction and communication problems. Many children with Pervasive Developmental Disorders are described as picky eaters, and this is thought to be associated with sensory problems (Gray, 2000).

Cerebral Palsy is a movement disorder resulting from central nervous system damage that occurs before age three. The movement problems may interfere with chewing, swallowing, and self-feeding in children with Cerebral Palsy (Mathisen et al., 1989).

Metabolism disorders include a variety of syndromes children are born with that result in stunted growth and may also be associated with other physical problems. Providing

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adequate nutrition for growth may be a problem with these children (Connecticut Birth to Three Nutrition Task Force, 2000).

Congenital heart disorders include a variety of chronic heart conditions children are born with, many requiring surgery before age five (DeMaso, Campis, Wypij, Bertram, Lipshitz, & Freed, 1989). Young children with cardiac problems frequently have difficulty keeping food down and gaining adequate weight for growth (Prontnicki, 1995).

Cleft lip and palate are relatively common birth defects occurring in one out of every six hundred fifty newborns. Cleft lip and palate can occur individually or together, and are a result of incomplete embryonic development of the lips or roof of the mouth (Glass & Wolf, 1998). Cleft lip and/or palate are usually repaired surgically before eighteen months (Glass & Wolf, 1998). Some children with cleft lip and palate have continued problems closing their lips to suck from a bottle after surgery, and others resist feeding because of over-sensitivity to touch in their mouths. Cleft lip and/or palate can occur alone or as part of a syndrome. For example, Pierre Robin Syndrome, one common cause of cleft lip and palate, is also accompanied by structural changes of the jaw and other disabilities.

Down Syndrome is a genetic problem associated with atypical development of the twenty-third chromosome which causes mental retardation and physical problems including a small jaw. Young children with Down Syndrome may have chewing difficulties related to their small jaw and delayed development (Prontnicki, 1995).

Failure-to-Thrive is a categorization describing children an overall weight below the third percentile norm for their age. An increased percentage of children with developmental problems have Failure-to-Thrive. Failure-to-Thrive may be caused by physical feeding problems and/or parent-child interaction problems (Lachenmeyer, 1995).

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Toddlers and preschoolers with disabilities may show a variety of distinct feeding problems. Feeding difficulties may occur in any or all of the four phases of eating: food intake and chewing; propelling food to the back of the throat and swallowing; passage of the food into the throat so it bypasses the windpipe, and peristalsis propelling the food to the stomach for digestion (Prontnicki, 1995). Feeding problems of young children with extremely low birth weight, developmental delays, and/or developmental disabilities may include food refusal, picky eating, inappropriate feeding behaviors, difficulty with breast and/or bottle feeding, cup drinking difficulties, self-feeding problems, loss of food or liquid from the mouth while eating, chewing problems; swallowing problems, choking difficulties; aspiration of food or liquid into the lungs; gastroesophageal reflux, vomiting, weight loss, lack of normal weight gain, lack of normal growth, and nutritional deficiencies (Connecticut Birth to Three Nutrition Task Force, 2000; Prontnicki, 1995).

Gastroesophageal reflux is movement of food or acid from the stomach back up into the esophagus that often causes a painful burning sensation. Research shows that approximately 75% of young children with severe Cerebral Palsy experience reflux, which can cause the child to resist feeding because of an association between eating and pain. Nutritional deficiencies can result from food refusal, a limited diet, or the inability to absorb certain nutrients. Although each of the feeding difficulties described is distinct, young children with developmental problems usually have a combination of these problems (Prontnicki, 1995).

The feeding difficulties of young children with developmental problems are usually caused by a number of interrelated factors. Burklow et al. (1998) found that the majority of children treated for feeding problems (85%) have multiple causes of their feeding

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difficulties including both organic and non-organic factors. In fact, the extreme complexity of children's feeding problems lies in the interactive nature of the biological, medical, and behavioral factors that influence and are influenced by feeding problems (Kedesdy &Budd, 1998). For example, a young child born with a cleft lip and palate may have feeding difficulties related to: 1) the initial difficulty sucking because of the cleft lip, 2) feeding resistance because of a power struggle that developed when the parents force fed the child before surgery so that he/she would gain enough weight to have the operation, 3) difficulty sucking because of the delay in normal feeding experiences before the cleft was repaired, and 4) resistance to spoon feeding after the operation (related to fear of pain from the cleft repair surgery).

This combined influence of physical and interpersonal factors contributing to the feeding problems of toddlers and preschoolers is supported by research (Mathisen et al., 1989). Mathisen et al. (1989) found that children who have organic chewing difficulties related to Cerebral Palsy often also have non-organic problems such as resisting feeding (because feeding has become a power struggle between the child and parents). In addition, if a young child has feeding problems that result in poor nutritional intake, the initial feeding problems may be worsened by malnutrition. Poor nutritional status can negatively effect an infant's physical and neurological development resulting in increased illnesses and a lack of energy for participation in feeding activities (Burklow et al., 1998; Connecticut Birth to Three Nutrition Task Force, 2000; Gray, 2000).

Young children with developmental disabilities who have severe nutrition problems or complications with oral feedings (e. g. significant aspiration or gastrointestinal problems) may be given alternate nutritional support through tube feeding. Tube feeding may also be

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used to provide nutrition during hospitalizations for severe medical problems. For tube feedings expected to be given for less than three months a nasogastric tube is inserted through the nose providing nutrition to the stomach. If tube feeding is expected to be used for longer than three months a gastrostomy tube is inserted into the stomach. Research suggests that tube feeding young children with developmental disabilities who need supplemental nutrition improves weight gain, nutritional status, and functioning of the immune system (White, Mhango-Mkandawire, & Rosenthal, 1995).

Feeding intervention approaches

Feeding and nutritional status have unique physical and psychological implications for young children with disabilities (Ernst & Young, 1993). Thus, feeding intervention is a necessary component of treatment programs for children with developmental and feeding problems (Cowen, 1998). Necessary intervention involves assisting parents to help their child with feeding (Connecticut Birth to Three Nutrition Task Force, 2000).

Treatment may be carried out by speech therapists, occupational therapists, nurses, nutritionists, special education teachers (also called developmental therapists), physical therapists, physicians, social workers, family therapists, or psychologists (Connecticut Birth to Three Nutrition Task Force, 2000). Often more than one professional is involved with a family, and no single professional discipline is responsible for addressing all areas of feeding problems. Several professionals often work together in a cooperative manner to provide feeding services (Connecticut Birth to Three Nutrition Task Force, 2000).

Many different feeding intervention approaches and techniques are used in feeding treatment with toddlers and preschoolers who have developmental and feeding problems. Depending on the specific feeding problems and the training of the early interventionists

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involved, the types of feeding treatment used can be classified as: oral-motor, compensation, behavioral, parent-child interaction, and social support approaches (Sheppard, 1995). These treatment classifications are not universally accepted, and a combination of these approaches often is used in feeding treatment, with some approaches stressed more than others (Sheppard, 1995).

The oral-motor approach is the most commonly used treatment approach for toddlers and preschoolers with developmental and feeding problems. Oral-motor strategies are chosen by sequentially evaluating the developmental level and quality of the child's feeding skills. Treatment involves selection of specific food types, feeding experiences, and oral-motor exercises to improve eating skills. Oral-motor strategies and exercises may be used to improve lip closure, chewing, swallowing efficiency, and problems of over-sensitivity to touch in the mouth that are interfering with food acceptance. Parents are usually taught specific oral-motor strategies and exercises and asked to carry them out regularly with their child (Sheppard, 1995).

Compensation approaches include the use of adaptive techniques and equipment to improve the child's functional eating. Adaptive techniques may include specific hands-on assistance provided by the feeder, such as stabilizing the child's jaw to make chewing easier. Adaptive equipment may include: adaptive seating to position the physically challenged child for easier eating, specially designed nipples to make sucking easier for children with cleft palate, and matting under the child's plate so it does not slide during self-feeding. Parents may be taught to implement the compensation strategies needed to make eating easier for their child (Sheppard, 1995).

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Behavioral approaches use a variety of behavior modification strategies to address resistance to accepting an appropriate amount and variety of food. Evaluation usually includes confirming that there are no unaddressed medical causes for the food refusal, specifically documenting the type and frequency of food acceptance, and determining the reinforcement methods that will be most effective. Behavior modification strategies may include: setting up an optimal environment for feeding, having the child eat with other children who readily accept the food offered, reinforcing food acceptance, limiting the times and duration during which food is offered, time out periods for inappropriate behavior, or forced feeding. Parents are taught to implement the behavior strategies and asked to implement them consistently and document their child's progress (Sheppard, 1995).

Problematic parent-child interactions can contribute to feeding difficulties in young children with developmental problems, but feeding dynamics are not a routine component of feeding evaluations (Satter, 1992). Parent-child interaction approaches usually involve observing and rating parent-child interactions, then teaching the parents to improve their feeding interactions. Parents are taught normal feeding development and optimal feeding interaction methods for their child. Feeding interaction strategies that make feeding more pleasant and enhance child development are modeled. Finally, the interventionist observes while the parent feeds the child, and provides suggestions and encouragement (Harris, 1989).

Parents with chronic feeding interaction problems may be so overwhelmed by their difficulties that they require social support before they can benefit from any other feeding intervention approaches. Social support approaches focus on reducing parenting stress so

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parents can be more responsive to their child. Specific social support strategies may include parent and family counseling, economic assistance, help with obtaining respite care, and support groups for parents of children with feeding problems. Strategies from any of the previously mentioned oral-motor, compensation, or behavioral approaches may also be used as part of the social support approach to reduce parenting stress (Harris, 1989; Satter, 1992).

Principles of Family-centered Early Intervention

Over the past three decades the focus of early intervention programs has been evolving from a child-focused concern with the toddler/preschooler's problems in isolation, to a family-centered focus on empowering parents to improve their child's developmental skills (Adams, Gordon, & Spangler, 1999; Kalobe, 1992). This transition to family centered early intervention was based primarily on the influence of parents and legislative mandates (Hanft, 1988). Part H of Public Law 99-457, which established and provided funding for the Birth-to-Three programs, includes mandatory provisions directing the programs to provide family-centered services (Hanft, 1988).

These family-centered early intervention services are based on a set of guiding principles and procedures, directing service provision for young children toward supporting the entire family in promoting the development of the child with special needs (Adams, Gordon, & Spangler, 1999; Kalobe, 1992). Most children under 3-years-old with feeding problems are provided services through the Birth-to-Three programs. Currently Birth-to-Three programs provide family centered services to the majority of children under three years old who have significant developmental risks, delays, or disabilities (Connecticut Birth to Three Nutrition Task Force, 2000; Crowley, 1995).

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In response to the family-centered mandates in the Birth-to-Three programs, early intervention providers have been gradually evolving their practices to provide services that are consistent with the principles of family-centered practice (Connecticut Birth-to-Three System, 1999; Foster & Phillips, 1992; Kalobe, 1992). Early intervention providers have begun to research and study family and developmental theories, primarily the family systems theory and the ecological and transactional models of human development (Case-Smith, 1998; Kalobe, 1992). However, serious concerns have been raised that family-centered early intervention services lack a theoretical foundation and research bases for their practices, and that early intervention providers lack a theoretical foundation to guide their assessments and interventions (Innocenti et al., 1993). In fact, there is little evidence that early intervention programs that involve parents are more effective than those that do not involve parents (Innocenti et al., 1993). There is a strong need expressed in the literature for the development of family-centered evaluation and intervention services that are grounded in a theoretical understanding of parenting and the family (Humphry, 1989; Innocenti, Hollinger, Escobar, & White, 1993).

Recognizing the potentially negative effects of feeding problems on families, feeding and nutrition services are provided as a related service to children in Birth-to-Three programs who require feeding intervention to promote their development (Connecticut Birth to Three Nutrition Task Force, 2000; Connecticut Birth-to-Three System, 1999; (Secrist-Mertz et al., 1997). Feeding and nutrition needs do not independently qualify children with developmental and eating difficulties for intervention services, but may be a component in the developmental assessments used to determine eligibility for Birth-to-Three services. Consistent with the family-centered approach, the purpose of nutrition

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and feeding intervention in the Birth-to-Three programs is to identify and support the feeding goals developed by the family. The belief is that through focusing on the families feeding goals, the parents will be fully invested in the feeding intervention, and feeding services will meet the needs of the family and child (Connecticut Birth to Three Nutrition Task Force, 2000).

By the time toddlers reach age three, they have been transitioned out of the Birth-to-Three Programs. For three to six year olds who require treatment, intervention is the responsibility of the public schools (Innocenti et al., 1993). Although public schools provide feeding treatment in school settings, they also embrace a family-centered model that involves parents by including them in treatment planning and home programs (Innocenti et al., 1993). The Birth-to-Three programs and public schools are the primary providers of feeding treatment to toddlers and preschoolers, and both propose to use family-centered treatment.

Family Systems Theory as a foundation for considering parents' feeding perceptions

This paper uses the family systems theory to consider factors related to parenting a young child with developmental and feeding problems. The parents and child are viewed as part of a family system " . . . comprised of an interdependent group of individuals who have . . . devised strategies for meeting the needs of individual family members and the group as a whole" (Anderson & Sabatelli, 1995, p.3). Feeding young children is an important maintenance task of the family, and the family devises strategies for accomplishing this task. Family members have varied roles in accomplishing the family tasks (Anderson & Sabatelli, 1995).

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Research suggests that parents significantly influence the development of young children with developmental problems. Since parents are most often the ones who feed toddlers and preschoolers, parenting factors are important in feeding intervention (Satter, 1992). Choosing an appropriate feeding treatment approach involves consideration of not only the child's developmental and feeding problems, but also the parenting factors influencing feeding (Humphry, 1989; Kraus, 1993; Werner, 1989). The next three sections of this chapter address parenting factors, based on family systems theory, that are related to parents' perceptions of their young child with developmental and eating problems.

Parenting factors when children have developmental and feeding problems

Parents' self-esteem and actions are influenced by how they view their competency in the parent role (Anderson & Sabatelli, 1995). For example, research suggests that some mothers of disabled children view their child's poor developmental performance as an indication that they are a poor caregiver and inadequate parent (Humphry, 1989; Imms, 1998). Since feeding is an important part of the parenting role, parents may view themselves negatively because their toddler/preschooler has eating problems. For example, research suggests that children's problematic feeding behaviors may influence parents' perceptions and consequently their responses to their child (DeMaso, Campis, Wypij, Bertram, Lipshitz, & Freed, 1990; Lachenmeyer, 1995).

Another factor that may affect the behaviors of parents who have young children with developmental and feeding problems is their sense of grief regarding their child's difficulties. Parents may experience a grieving process that includes denial, anger, bargaining, or depression related to their child's disabilities. The grieving process may be

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especially severe for parents who perceive their child has severe developmental disabilities and/or feeding problems. There is little evidence that the grief process is sequential or that parents achieve a stage of permanent acceptance of their child's disabilities, so parents may periodically experience greater or lesser distress related to this grief process (Humphry, 1989).

Because parents most often are responsible for feeding, it is important to consider how feeding problems may negatively influence parents' interactions with their child (Harwood, Miller, & Irizarry, 1995; Kedesdy & Budd, 1998). Parent-child interactions during feeding involve the basic teaching and learning skills which are the foundation for the child's developmental progress (Humphry, 1989). A young child's developmental and feeding problems can interfere with this parent-child teaching and learning process, frustrating both parent and child and interfering with their relationship (Mathisen et al., 1989).

Parenting stress when children have developmental and feeding problems

Within the context of parenting, stress is the pressure experienced by parents to modify their strategies for executing basic family tasks. Parents normally experience increased stress with the birth of a child, an expected developmental transition in the life of a family. Having a young child with developmental and feeding problems can be viewed as a nonnormative stressor event superimposed on the normative stressor event of having a new child (Anderson & Sabatelli, 1995).

Several evaluations are available to assess parenting stress, including the Parenting Stress Index (PSI) and the Parenting Stress Index/Short Form (PSI/SF). These self-report measures assess a parent's degree of stress associated with his/her role as a parent. A

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great deal of information regarding parenting stress has been learned through research involving the PSI and PSI/SF (See Appendix A), as well as other measures of parenting stress (Abidin, 1995a).

Research indicates that parents of young children with developmental and feeding problems have significantly greater levels of parenting stress than parents of typically developing children (Humphry & Rourk, 1991; Innocenti et al., 1992; Secrist-Mertz, Brotherson, Oakland, & Litchfield, 1997; Welch, 1996). As in the majority of studies with parents whose children had developmental disabilities but no specific feeding problems, Humphry & Rourk (1991) found parents of children with the feeding problem of reflux had significantly higher levels of parenting stress, but the higher stress was only related to child difficulty characteristics.

Research comparing parents of children with developmental disabilities with and without feeding problems shows mixed results. Adams et al. (1999) studied 32 mothers of children with disabilities. No significant differences in stress were found between mothers of children with disabilities and feeding problems, and mothers of children with disabilities and no feeding problems (Adams et al., 1999). However, research by Welch (1996) suggests that parents of young children with more severe developmental and feeding problems experienced greater parenting stress than parents of children with milder developmental and feeding problems (Welch, 1996). Welch (1996) proposes that feeding interactions may be a distinct parenting task in which child disability characteristics are particularly important influences on overall parenting stress.

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Effectively coping with parenting stress

When considering stress as a parenting factor it is necessary to consider the parent and family's ability to cope effectively with stress. Coping is the use of problem solving strategies to respond to stress. Parents and families only experience the negative emotion of distress if stress levels exceed their ability to cope effectively (Anderson & Sabatelli, 1995).

Affleck and Tennen (1991) studied how mothers' perceptions and coping strategies at the time their infant was discharged from the Neonatal Intensive Care Unit (NICU) predicted their levels of distress and infant's development at 18 months old. A significant positive correlation was found between the developmental outcome of the infants and their mothers' expectations in the probability that their child would develop optimally. The medical severity composite was not significantly correlated with the mother's' expectancies or childrens' outcomes. Mother's who most frequently used escapist coping (e.g., wishful thinking, avoiding social interactions) had children who developed less optimally. Minimizing the severity of their child's difficulty in the NICU predicted greater distress for mothers whose children were eventually diagnosed with developmental disabilities. The search for meaning was the only coping strategy that predicted less maternal distress (Affleck &Tennen, 1991).

Effective coping depends on having adequate coping resources. Coping resources include education, economic well-being, support from family members, and community social support (Anderson & Sabatelli, 1995). Education and economic status are two important coping resources. Research indicates that lower income and lower levels of education are related to increased parenting stress (Paradise et al., 1999). Based on a

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study of 4, 515 parents of toddlers and preschoolers with chronic ear infections, Paradise et al. (1999) found a significant inverse relationship between socioeconomic status (including income and educational levels) and parenting stress on the Parenting Stress Index Short-Form. Similarly, parents of children with failure-to-thrive who had lower incomes and lower levels of education were found to have significantly greater parenting stress than parents of failure-to-thrive children who had higher incomes and education levels (Singer et al., 1989).

Social support has been found in repeated research to mediate stress and buffer the impact of crises and chronic stressors (Humphry, 1989; Innocenti et al., 1992). Support is multidimensional. Support has affective, cognitive, and instrumental elements and can meet parents' needs for intimate interactions, information, advice, and tangible assistance (Affleck, Tennen, & Rowe, 1991).

Perceived support from spouses and other family members is also an important coping resource (Anderson & Sabatelli, 1995). Research regarding parents of children with and without developmental problems found lower parenting stress was significantly related to higher perceived support from spouses (Abidin, 1995a). Research with parents of toddlers and preschoolers with developmental disabilities also showed that lower levels of stress were significantly related to greater perceived spousal support (Beckman, 1991; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999).

Research also supports the effectiveness of specific forms of community social support in enabling parents to cope effectively with parenting stress (Humphry, 1989). Important types of community social support include respite care, assistance with child-care tasks, and parent support groups (Humphry, 1989). However, in order for parent support

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groups and other types of community social support to help parents cope effectively with stress, the groups must be perceived by the parents as supportive. Research suggests that parents of developmentally disabled children with the greatest feeding problems experienced the least perceived social support from attending parent support groups (Secrist-Mertz et al., 1997).

When feeding treatment services are provided which enable parents to cope effectively with their child's feeding problems, they serve as a social support that reduces parenting stress (Humphry, 1989). Feeding interventions are most likely to provide social support if professionals demonstrate an understanding of the unique stresses experienced by each family. Understanding how parents perceive and cope with their child's feeding problems enables professionals to better assist families in successfully adapting to these problems (Handleman, 1995).

However, feeding treatment also has the potential of providing no social support (Beckman, 1991). For example, Beckman (1991) found no relationship between parent's receiving family-centered intervention services for their toddler or preschooler and reduced parenting stress. Feeding intervention also has the potential of increasing parenting stress (Humphry, 1989). For example, Humphry (1989) states that if early intervention places demands on parents that they feel they can't meet, such as extensive home programs, early intervention can increase parenting stress.

Exchange Theory as a foundation for considering parents' perceptions of feeding

Parents' perceptions of feeding are influenced by the child's developmental and feeding problems and the parent's perceptions of these problems (Kedesdy &Budd, 1998; Sparling & Rogers, 1985). It appears that parent's feeding perceptions involve a dynamic

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reciprocal interaction between the infant's physical characteristics and parent factors (Burklow, Phelps, Schultz, McConnell, Rudolph, 1998; Lachenmeyer, 1995).

Exchange Theory provides a foundation for understanding parents' feeding perceptions because it provides a framework for understanding the patterns of fairness, decision making, and power in intimate relationships that are applicable to both the parent-child relationship, and the marital relationships which often impacts the parent-child relationship. Exchange Theory is also particularly applicable for understanding feeding because it is capable of addressing both the micro- and macro-level behaviors that affect feeding, as well as the behavioral and psychological patterns of interdependence found in parent-child and marital relationships (Sabatelli & Shehan, 1993). Social exchange theory will be used in this dissertation to consider parent's perceptions of feeding.

Social exchange theory suggests a framework for considering an individual's overall satisfaction in intimate relationships such as marriage and parenting. Social exchange theory describes an individual's satisfaction with intimate relationships as being guided by the Comparison Level (CL), a standard people use to assess a relationship's costs and rewards. The CL is set in terms of ones' expectations of what is realistically obtainable, and is based on an individual's awareness of societal norms and their past experiences. Expectations and the resulting overall satisfaction can fluctuate over time, as an individual's experiences in the relationship constantly feed back into the CL (Sabatelli & Shehan, 1993).

Based on this concept of a comparison level standard that is used by individuals in percieving their overall satisfaction with aspects of a relationship, the Parental Comparison Level Index (PCLI) self-report measure was developed (Sabatelli & Shehan, 1993). The

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PCLI evaluates overall parenting satisfaction using two subscales composed of questions that assess the costs and rewards of parenting. Consistent with the social exchange perspective for assessing social relationships, both the gratifying and burdensome aspects of parenting are assessed, with questions using an individual's subjective expectations as the baseline for assessment (Waldron-Hennessey & Sabatelli, 1997).

From an exchange perspective, a parent's overall perception of feeding satisfaction would depend on how they perceived the relationship between the costs and rewards of feeding (Anderson & Sabatelli, 1995). Consistent with this view, research with parents of disabled children suggests that the overall perceptions of these parents involve a complex combination of positive and negative feelings (Larson, 1998). Larson (1998) found the overall perceptions of mothers with severely disabled children involved paradoxical feelings towards their role. The mothers experienced joy through their relationship with their child, as well as sadness over their child's physical problems (Larson, 1998).

Use of Social Comparison Theory for considering parents' perceptions of feeding

Social comparison theory addresses the ways in which individuals use cognitive processes (Croyle, 1992) involving social comparisons to cope with stressful events (Taylor, Buunk, & Aspinwall, 1990). People may use downward social comparisons (comparing themselves with others who are less fortunate or capable) or upward social comparisons (comparing themselves with others who are more capable or better off) in attempts to cognitively mediate stress. However, upward comparisons do not necessarily lead to negative affect, and downward comparisons to positive affect (Hemphill & Lehman, 1991).

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The critical factor may not be the type of comparison that is made, but an individual's perception of what the observation means (Hemphill & Lehman, 1991). Downward social comparisons can affect an individual positively if they focus on their comparative superiority or good fortune, or negatively if they perceive it as an indication that their own situation can get worse. Likewise upward social comparisons can affect an individual positively if they focus on the possibility that they can become better off than they are currently, or negatively if they focus on their current relative inadequacy and misfortune relative to others (Taylor, Buunk, & Aspinwall, 1990).

Britner, Gill, LaFleur, Pianta, and Marvin (2000) classified parents of children ages 15 to 50 months old who had cerebral palsy or epilepsy as resolved or unresolved with regard to their child's diagnosis based on the Reaction to Diagnosis Interview. Resolved mothers had significantly larger friendship networks, and significantly less parenting stress (both $p < .05$) than Unresolved mothers. Resolved mothers were significantly more likely to mention accepting the child 'as they are' ($p < .01$). Resolved mothers were significantly less likely to use positive social comparisons, and significantly less likely to avoid mentioning the characteristics of their disabled child than Unresolved mothers. However, no significant differences were found in the use of downward social comparisons by mothers who were Resolved and Unresolved.

Parents' perceptions of the costs of feeding

In order to effectively assist parents who have a young child with developmental and eating problems, it is important to understand their perceptions of feeding as well as the coping strategies they use to manage their stress related to feeding perceptions. From an exchange perspective, feeding perceptions would involve the perceived costs and rewards

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of feeding. In considering the costs of feeding for parents of toddlers and preschoolers with disabilities, one important factor is the significant amount of time required for feeding. Imms (1988) found that compared to parents of typical children, parents of children with eating problems spend significantly more time on feeding (Imms, 1988). A significantly greater number of mothers of children with disabilities report that their child is a very slow eater and they are worried he/she is not eating enough (Imms, 1988; Reilly & Skuse, 1992). Secrist-Mertz et al. (1997) found a small positive correlation ($p<.10$) between total daily time taken for oral feeding and parental stress. Thus, the greater time required for feeding young children who have developmental and feeding problems may be related to increased parenting stress.

A second feeding cost reported by parents of children with developmental and feeding problems is the difficulty and unpleasantness of feeding their child. Reilly and Skuse (1992) compared reports on feeding by twelve mothers of 15 to 39 months old children who had cerebral palsy and oral-motor dysfunction, and a matched control group of mothers whose children had no disabilities. Significant differences were found between the two groups of mothers. Mothes whose children had disabilities more often reported that feeding was very difficult and unenjoyable (Reilly & Skuse, 1992).

A third feeding cost for parents described in the literature is their child having specific feeding behaviors that are assumed to be problematic. One study of parents whose children had Cerebral Palsy and feeding problems found that the most commonly reported difficulties were: mealtimes of over 45 minutes (40%), difficulty chewing and/or swallowing (40%), and eating small amounts of food (14%) (Dahl et al., 1996).

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Clark et al. (1998) used a nutrition screening with parents of 425 infants from birth to three years old with developmental problems. The highest percentage of feeding problems parents' described as occurring more than three times monthly were: Intake of less than 16 oz. or more than 32 oz. of milk/formula-26%; gagging-16%; weight loss or lack of weight gain-14%; problematic behavior (described as food refusal/aversion, pickiness, and tantrums)-13%; and not eating an entire food group-11% (Clark et al., 1998).

Parents' perceptions of the rewards of feeding

Parents of young children with developmental and feeding problems stress the importance of feeding being enjoyable, providing nurturance, and maintaining normalcy (Brotherson et al., 1995). Considering this perceived importance parents of disabled children appear to place on positive feeding experiences, it is problematic that only one (Brotherson et al., 1995) of seven studies regarding parents' feeding perceptions considered the rewarding aspects of feeding (Clark et al., 1998; Dahl et al., 1996; Innocenti et al., 1993; Meyer, Coll, Lester, Boukydis, McDonough, & Oh, 1994; Reilly & Skuse, 1992; Secrist-Mertz et al., 1997; Sparling & Rogers, 1985).

Importance of parents' perceptions for family-centered feeding intervention

An understanding of parents' feeding perceptions is important in evaluating and treating young children with developmental and feeding problems. Since most infant feeding problems are initially identified through parental reports, an increased understanding of parents' feeding perceptions could enhance professionals' abilities in the early identification and treatment of infant feeding difficulties (Forsyth et al., 1985). An understanding of parents' perceptions of their young child's feeding behaviors provides a foundation for affective family-centered feeding intervention by clarifying parents' feeding

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concerns, pleasures, satisfaction, and goals (Bernheimer & Keogh, 1995; Crowley, 1995; Deal et al., 1994). Focusing on parents' feeding concerns and goals promotes parents' investment in feeding intervention.

It is crucial that parents view feeding intervention as relevant to their needs and are invested in it. The literature suggests that if parents are not invested in feeding treatments they will not follow through on the required interventions (Reilly & Skuse, 1992; Humphry, 1991). This lack of parental investment in feeding treatments appears to be contributing to the ineffectiveness of nutrition interventions (Reilly & Skuse, 1992). An understanding of parents' feeding perceptions is therefore an important component of feeding intervention to promote feeding development.

Research involving family-centered feeding intervention

Despite the predominance of family-centered treatment, there are few studies that evaluate the effectiveness of family-centered treatment specific to feeding. In one of these studies, Meyer, Coll, Lester, Boukydis, McDonough, and Oh (1994) used parents' reports of their preterm infant's feeding problems as the bases for providing individualized family-based feeding treatment. Intervention included: modeling positive feeding interactions; parent support and counseling to improve parent-infant interactions and family functioning; and support with transition from the hospital. Mothers in the treatment group had less depression and parenting stress on self-report measures, and showed improved parent-infant interactions on double-blind observation measures. The infants in the intervention group showed significantly fewer negative feeding behaviors (e.g., grimacing, gagging). The researchers concluded that the family-based feeding intervention positively influenced parental adaptation and interactions. However, the significance of the original

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feeding and developmental problems of these infants was not well established, and a significant number of preterm infants spontaneously recover from developmental and feeding problems (Meyer et al., 1994).

Innocenti et al. (1993) conducted a randomized experimental study comparing early intervention programs with and without a parent involvement component. Seventy 3 to 6 year olds with developmental disabilities who attended a preschool program participated in the study. The parent involvement group received classes on child development, specific early intervention treatment strategies for the child, and a parent support group for one school year. Feeding treatment was included in the intervention, but it was not stated that all of the children had feeding problems or received feeding treatment. The group receiving the supplemental parent involvement showed small but significant improvement in child development outcomes, and perceived parent support (on self-report measures) immediately after the intervention program. However, these significant gains were not maintained one year later. Only parents' increased understanding of the relationship between environmental influences and child developmental progress was still significantly different for the parent involvement group one year after the intervention program. Results of the study are limited in that some of the treatment group members continued to receive a parent involvement program in the year preceding retest while others did not (Innocenti et al., 1993).

Most feeding intervention programs for young children with disabilities, regardless of the type or setting, currently describe themselves as family-centered. However, Innocenti et al. (1993) raise serious questions regarding the degree to which these family-centered feeding intervention programs address the needs and concerns of parents. It appears that

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many early interventionists do not apply a theoretical understanding of parent factors (e.g. family systems theory, attachment theory, or family stress theory) to their treatment of feeding problems with toddlers and preschoolers. While family-centered practice is the goal of most feeding intervention programs, often parents' perceptions are not fully understood or measured.

As a result, the effectiveness of the parent intervention component of these programs has been questioned. Innocenti et al. (1993) state there has been " . . . very little evidence that early intervention programs that involve parents were more effective than those which did not involve parents" (p. 307). Given the mandate of the Birth-to-Three Program that feeding intervention involve parents and focus on parents' feeding concerns (Connecticut Birth to Three Nutrition Task Force, 2000), it is important for feeding intervention programs to consider how parents' perceptions effect feeding intervention (Innocenti et al., 1993).

Summary of the literature review

This literature review describes common developmental and feeding problems of toddlers and preschoolers. Parent factors affecting parents' perceptions of their child with developmental and feeding problems are described, with an emphasis on parenting stress. Research suggests that parents with young children who have developmental and feeding problems experience greater stress than parents of typically developing children.

Research regarding parents' perceptions of their child's developmental and feeding problems are then discussed based on family systems and social exchange theories. Parents with children who have developmental and feeding difficulties have identified specific difficulties related to feeding. The feeding problems most frequently identified by parents

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as problematic included their child not eating enough, taking a long time to feed, and experiencing oral-motor problems (e.g., gagging, and having difficulty with chewing).

However, the literature on feeding focuses on negative feeding behaviors, and little information was found regarding the positive aspects of feeding for parents of children with developmental and eating problems. Overall, parents of young children with developmental and feeding problems were significantly more likely to describe their child's behavior as atypical and feeding as unenjoyable.

Intervention programs for young children with developmental and feeding problems are also described. While a family-centered approach to feeding treatment is currently used, its theoretical foundations have been questioned and there is a lack of research supporting the effectiveness of this approach in reducing parents' stress related to feeding. A greater understanding of parent's perceptions of feeding appears to be needed to enable early intervention programs to more effectively implement family-centered feeding intervention to reduce parents' negative feeding experiences.

Research Questions

This paper considers parents' feeding experiences based on the family systems and social exchange theories. Feeding is considered as a maintenance task involving primarily the parent and child, but affecting the entire family system. From this family systems and exchange theory perspective parents' perceptions of feeding are crucial considerations for feeding intervention with toddlers and preschoolers. Parents' overall satisfaction with feeding is conceptualized as depending on the relationship between parents' perceived costs and rewards of feeding.

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The aim of this study is to describe parents' perceptions of feeding their infant/toddler who has developmental and eating problems including: 1) their perceptions of feeding costs, rewards, and overall satisfaction, 2) the relationship of specific feeding costs and rewards to parenting stress, and 3) the impact of feeding intervention. Parents' feeding experiences are viewed from the perspective of family systems and social exchange theory. Parents' feeding perceptions are considered as they relate to family-centered feeding intervention in order to answer the following research questions:

Question 1: What components of feeding do parents of toddlers/preschoolers who have developmental and eating problems describe as difficult and frustrating?

Question 2: What components of feeding do parents of toddlers/preschoolers who have developmental and eating problems describe as rewarding?

Question 3: How do parents of toddlers/preschoolers who have developmental and eating problems rate their overall satisfaction with feeding?

Question 4: How do parents' perceptions of feeding costs, rewards, and overall satisfaction with feeding relate to parenting stress?

Question 5: What are parents' perceptions of the overall impact of the Birth-to-Three programs' feeding interventions?

Relevance of the study and its findings

This paper provides relevant information regarding parents' feeding perceptions that is not well addressed by the existing literature. One of the areas addressed in this paper is parents' perceptions of the rewarding aspects of feeding. The rewarding aspects of feeding appears to be an important component of parents' perceptions in feeding young children with developmental and eating problems (Brotherson et al., 1995; Clark et al.,

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1998; Dahl et al., 1996). This study helps to address a gap in the research by describing parents' perceptions of positive feeding experiences with their toddler/preschooler who has developmental and eating problems. Understanding parents' perceptions of rewarding feeding experiences may prove helpful for planning feeding treatment to promote a more positive perception of feeding by parents (Bernheimer & Keogh, 1995; Crowley, 1995; Deal et al., 1994).

A second contribution of this paper is its consideration of parents' perception of their degree of frustration related to specific feeding behaviors. Previous studies have reported parents perceptions of the frequency of occurrence of presumably problematic feeding behaviors (Clark, Oakland, & Brotherson, 1998; Dahl, Thommessen, Rasmussen, & Selberg, 1996). However, whether and to what degree parents find these behaviors problematic is unknown. Through having parents rate their perceived frustration related to presumably problematic feeding behaviors, this paper provides unique information regarding parents' perceptions of their feeding costs.

A third contribution of this study is its use of open-ended questions, enabling parents to generate a description of their greatest feeding costs, rewards, and needs. This addresses the need expressed by Forsyth, Leventhal, and McCarthy (1985) for using open-ended questions to provide an understanding of the meaning parents give to problematic feeding behaviors. Little research was found that asks parents of children with developmental and feeding problems to generate a description of the feeding behaviors they find most problematic (Forsyth et al., 1985).

A fourth contribution of this paper is its description of the relationships between parents' feeding perceptions and overall parenting stress. Given the established

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relationship between overall parenting stress and developmental outcomes, significant relationships between parents' perceptions of their child's feeding behaviors and parenting stress may suggest the need for a greater emphasis on family-centered feeding intervention and/or identify specific feeding behaviors that should be considered in feeding treatment to reduce parenting stress.

This paper also offers a unique contribution through its approaching parents' feeding perceptions from the perspective of family systems and social exchange theories. Consistent with these perspectives, the paper utilizes parent self-report measures to reflect parents' perceptions of feeding and overall parenting stress, rather than measures that involve observations by outside experts. Influenced by the exchange theory perspective, consideration is given to parents' perceptions of feeding costs, rewards, and overall feeding satisfaction (Waldron-Hennessey & Sabatelli, 1997).

Finally, this study investigates the concerns raised by Innocenti et al. (1993) regarding the degree to which family-centered feeding intervention programs address the needs and concerns of parents. As noted in the literature review, research suggests that feeding intervention with young children who have developmental and feeding problems is more effective if it addresses the goals parents' perceive are most important. This paper considers parents' perceptions of feeding intervention and their relationship to parenting stress.

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CHAPTER III

METHODS

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1. Participants

Participants were 31 parents with 15 to 52 month old children (mean age 28 months) identified as having feeding difficulties and developmental problems qualifying them for participation in the Birth-to-Three programs. All families were participants or former participants in the Birth-to-Three System, 27 in Connecticut and 4 from out of state (one each from New York, New Jersey, Florida, and North Carolina). Twenty-five (81%) were currently in the Birth-to-Three Program at the time of the interview; while 6 (19%) had graduated.

Interviews were done with the parent who was the primary feeder and identified within the family as doing the most feeding. In order to support families in improving their child's eating skills, the focus of this study was on the perceptions of parents, rather than on observation of the children's behavior.

The sample was drawn primarily from within the Connecticut Birth-to-Three program and was a convenience sample. Efforts were made to include families of diverse socioeconomic backgrounds representative of the Birth-to-Three program participants. All of the target children had extremely low birth weight, developmental delays, or developmental disabilities consistent with the criteria for participation in Connecticut's Birth-to-Three Program. Birth-to-Three Program agencies participating in this study included: Rehab Associates, Reach Out, Inc., Kidsteps, Learn: Partners for Birth to Three, and Early Connections Northwest and Eastern Connecticut Regions.

1a. Criteria for Inclusion: Criteria for inclusion in the study were 1) parents had to speak English (due to the unavailability of an interpreter); 2) children had to eat orally, so that eating skill concerns were relevant; 3) children had to meet eligibility requirements for

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participation in the Birth-to-Three Program, and 4) children had to have a feeding problem.

The operational definition of developmental problems for this paper is extremely low birth weight (less than 2.2 pounds), developmental delays as noted from standardized testing of -2 standard deviations in one or more developmental areas or -1.5 in two or more areas, or a major diagnosis. All of these criteria for developmental problems are factors known to be related to increased incidences of feeding problems, and consistent with the criteria for inclusion in the Connecticut Birth-to-Three Program at the time of the study (Connecticut Birth to Three Nutrition Task Force, 2000).

Feeding problems are operationally defined in this paper as documentation in the child's evaluation record of a feeding, eating, and/or nutritional problem reported by the parent, therapist, and/or physician. Children who received tube feeding in addition to oral feeding were included as long as they took some food orally on a regular basis.

Parents whose children had cleft lips or palates that had not been surgically repaired were not included in the study, but children with cleft lips or palates that had been surgically repaired were included. It was presumed that the feeding problems experienced by children with cleft lips or palates that have not been surgically repaired may be distinct from other children with developmental and eating problems.

1b. Child Factors: The target children who met the criteria for this study had a variety of diagnoses, which were organized into seven diagnostic categories (see Table 1). Diagnostic categorizations were organized in hierarchical order (See Appendix I, section II for releability information). Diagnoses of the children were categorized as: Pervasive Developmental Disorder and/or Autism (19%), Cerebral Palsy (39%), Cleft lip and/or

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palate with surgical correction (6.5%), Down Syndrome (7%), Cardiac problems and developmental delay (6.5%), Developmental delay with no cardiac problems (19%), and Extremely low birth weight (3%). Twenty-three (74%) of the subjects were fed only by mouth, while 8 (26%) were tube fed and fed orally.

Only one of the 8 tube fed children had a nasogastric tube, the other 7 were fed by a gastrostomy tube. Regarding current disabilities 6 (21.4%) were legally blind (N=28), 8 (28.6%) were hearing impaired (N = 28), 3 (11.1%) had shunts (N = 27), 10 (34.5%) had a seizure disorder (N = 29), and 4 (14.3%) had experienced a seizure in the past 6 months (N = 28).

Ages of the target children ranged from 15 months (1 year 3 months) to 52 months (4 years 4 months), with a mean of 27.7 months and a mode of 34 months (SD = 9.1). Twenty-five (81%) of the target children were boys and six (19%) were girls. The children received a mean of 8 Birth-to-Three treatment session weekly, ranging from 1 to 31 sessions weekly. A treatment session was defined as a treatment of 45 to 60 minutes. Using this criterion, a three hour session was calculated as three treatments.

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Table 1

Diagnostic Categories of Toddlers & Preschoolers

Diagnoses	Number	Valid Percent
PDD and/or Autism	6	19
Cerebral Palsy	12	39
Cleft lip and/or palate (surgically corrected)	2	6.5
Downs Syndrome	2	6.5
DD and cardiac or metabolic diagnosis	2	6.5
Developmental Delay	6	19
Extremely low birth weight	1	3

1c. Parent/family Factors: All of the primary feeders were parents of the target child, including 29 mothers (93.5%) and 2 fathers (6.5%). Primary feeders had a mean age of 34 years, ranging from 19 to 43 years old. Twenty-three (74%) were married, seven (23%) were single, and one (3%) was divorced. Twenty-three (74%) of the primary feeders were white, four (13%) were Hispanic, three (10%) were black, and one (3%) categorized herself using the "Other" category to specify that she was Hispanic white. Fourteen (45%) of the primary feeders were college graduates, nine (29%) had vocational school/some college, four (13%) had a graduate degree, two (6.5%) were high school graduates, and two (6.5%) had some high school.

The average total time required for daily feeding of the target child ranged from one-half hour to eight hours, with a mean of 2.4 hours (mode = 2.0 hours, SD = 1.5 hours). The mean percent of feeding done by the primary feeder was (65%), ranging from (22%) to (100%). Spouses/partners of the primary feeder did an average of (16%) of the feeding, ranging from (0%) to (50%). All other feeders combined did an average of 16%

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of the total feeding, ranging from (0%) to (75%). The primary feeders were employed a mean of 20 hours weekly, ranging from 0 to 45 hours.

Twenty-five (86%) of the households included 2 adults, three (10%) 1 adult, and one (3%) 4 adults. Thirty-five percent of the households had 1 child besides the target child, (31%) had no other children, (21%) had 2 additional children, (10%) had 3 children, and (3%) had 8 children. The mean percentage of time that child-care was provided only by the parents was 83%, while 10% of the time the children were cared for in day care centers, 5% of the time by baby sitters or nurses in the home, and 2% of the time by relatives.

Twelve (41%) of the subjects had an annual household income of $51,000-100,000, six (21%) $26,000-50,0000, five (17%) less than $15,000, four (14%) $101,000-200,000,and two (7%) $15,000-25,000 (see Table 2).

Table 2

Annual Household Income

Income Range	Frequency	Percent	Valid Percent	Cumulative Percent
Less than $15,000	5	16.1	17.2	17.2
15,000-25,000	2	6.5	6.9	24.1
26,000-50,000	6	19.4	20.7	44.8
51,000-100,000	12	38.7	41.4	86.2
101,000-200,000	4	12.9	13.8	100.0
Total	29	93.5	100.0	100.0

2. Instrumentation

Five instruments were used for this study. As shown in the Matrix of Instrumentation (see Table 3), the five instruments collectively gathered variables in the five major areas

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listed in the left column of the matrix: 1. Demographics, 2. Perceptions of Feeding Difficulty, 3. Perceptions of Feeding Rewards, 4. Impact of the Birth-to-Three Programs' feeding intervention and overall feeding support on the primary feeder, and 5. Parenting stress.

Table 3

Matrix of Instruments Used and Information Collected

Information Collected	Demographic Questionnaire	Information About Yourself	Feeding Questionnaire	Family Demographic & Medical History	Parenting Stress Index-Short Form
1.Demographics	X	X		X	X
2.Perceptions of Feeding Difficulty		X	X		
3.Perceptions of Feeding Rewards			X		
4.Impact of the Birth-to-Three Programs' feeding intervention and overall feeding support on the primary feeder			X	X	
5.Parenting Stress					X

2a. Demographic Questionnaire: The parent identified within the family as doing the most feeding was interviewed to update and clarify medical and developmental information from the child's Birth-to-Three record, and to gather demographic information about the family not available from the record (see Demographic Questionnaire, Appendix B). Information gathered from this interview included the target child's recent medical problems, childcare arrangements, and the percentage of feeding done by the primary feeder. The Demographic Questionnaire and the Information about Yourself form (Appendix C) gathered information about the nature of the child's microsystem of family

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and day care providers. This information was vital in gathering relevant variables that impact feeding. The relevance of these demographic variables is justified by: the diversity of the Birth-to-Three population, base of knowledge regarding the significant influence of demographic variables, and the scientific relevance of social constructs (e.g. ethnicity, race, gender, socioeconomic status) on both development and the institutions which provide the contexts for development (Entwisle & Astone, 1994).

2b. Information About Yourself: This self-report instrument was used to gather demographic information about the primary feeder, including the family's annual income (Appendix C). Certain items in this section were the same as or influenced by items related to life stress from the PSI (Abidin, 1990). Consistent with the suggestions of Entwisle and Astone (1994), subjects were asked to identify race and ethnicity using a self-report instrument, and an "other" category was added which allowed subjects to specify race and ethnicity beyond those included U.S. Bureau of Census scheme of five categories e.g. non-Hispanic white, Hispanic, black, Native American, and Asian and Pacific Islander (1). Race and ethnicity information was limited to the primary feeder, as this individual was the focus of this research.

2c. Feeding Questionnaire: The Feeding Questionnaire (Appendix D) was developed based on a review of the literature and the researcher's clinical experience with families who have a child with developmental disabilities and feeding difficulties. Items were chosen after analyzing a variety of feeding assessments to determine the specific aspects of feeding that should be assessed.

The five major topics covered by the Feeding Questionnaire are Child sensory-motor behaviors (Section A), Parent feeding interaction behaviors (Section B), Child behavioral

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characteristics (Section C), Parent/child interactions (Section D), and Functional feeding/eating skills (Section E).

The Feeding Questionnaire consisted of open-ended and scaled questions that attempted to comprehensively cover all the relevant aspects of feeding from an occupational transactional orientation. Specific problematic feeding behaviors were rated by the primary feeder according to frequency of occurrence, and the degree of frustration experienced by the parent when they occurred. Through open-ended questions parents also described the feeding behaviors they perceived as most problematic and for which they needed the greatest support. Similarly, parents rated the frequency with which their child demonstrated age appropriate feeding behaviors and described through open-ended questions the aspects of feeding they found most rewarding.

The open-ended questions and scale scored items of the Feeding Questionnaire were primarily based on the CEBI "Children's Eating Behavior Inventory" (Archer, Rosenbaum, & Streiner, 1991). Other feeding assessments that were used to develop the Feeding Questionnaire, listed from most to least influential, were the Parental Comparison Level Index (Waldron-Hennessey & Sabatelli, 1997), Clark Nutrition Screening (Clark et al., 1998), Parenting Stress Index (Abidin, 1990), Quality of Life Issues Regarding Feeding (Brotherson et al., 1995), FIRST Assessment (Sparling & Rogers, 1985; Sparling, 1999), NCAST Feeding Scale (Barnard, 1994), Connecticut Birth-to-Three Nutrition Survey Proposal (Connecticut Birth to Three, 1999), the Interview About Feeding (Pridham, 1999), Oral-Motor Assessment (Sheppard, 1995), and the SOMA "Schedule for Oral Motor Assessment" (Reilly et al., 1995). A list of the behaviors assessed by the Feeding

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Questionnaire, and the feeding evaluations that were found which address these behaviors, are identified in Table 4.

An in-person semi-structured interview conducted in the home was chosen as the best method for gathering specific information regarding parents' perceptions of their child's feeding behaviors. Interviews in the parents' homes were chosen because they allow the most interaction of any survey method, and provide a greater understanding of the context of parent responses in the home environment which is most relevant to feeding young children (Azzi-Lessing, 1996).

A semi-structured interview format, using both a rating scale and open-ended questions, was chosen for the interview. The inclusion of open-ended questions allowed parents to elaborate on responses and promoted rapport between the interviewer and respondent. A wider range of in-depth responses was more likely because open-ended questions were used, which may have provided a better understanding of the parents' perspective by including the context in which it exists. By also including the rating scales, greater consistency was possible than if only open-ended questions were used. The inclusion of the rating scale offered improved reliability, making data analysis less time consuming so more subjects could be included for greater generalizeability of responses (Azzi-Lessing, 1996).

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Table 4

Feeding Related Behaviors Included in Feeding Assessments

Feeding Related Behaviors	CEBI	Clark Nutrition Screening	Clinical	FIRST	NCAST	Oral-Motor Shep-pard
A. Child Sensory-Motor Oral Behaviors						
1. Age appropriate chewing	X	X	X	X		X
2. C (Child) eats chunky foods	X		X			X
3. C eats solids after 1 year		X	X			X
4. C lacks good functional suck		X	X			X
5. C withdraws to touch on face			X	X		X
6. C dislikes tooth brushing			X	X		
7. C able to pucker/kiss				X		
8. C able to blow				X		X
9. C able to vocalize "mm" and "bb"				X		X
10. Lips take food off spoon of 16 months			X	X		X
11. C opens mouth I as spoon approaches				X	X	
12. Lips closed so no leakage's			X	X		X
13. Tongue propels food out by accident			X	X		X
14. Munching after 6 months			X	X		X
15. Graded jaw movements			X	X		X

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B. Parent Feeding Interaction Behaviors						
1. P (Parent) talks to C				X	X	
2. P smiles at C				X	X	
3. P makes eye contact with C				X	X	
4. P comments on C signals			X	X	X	
5. P able to interpret C signals			X	X	X	
6. P responds to C distress			X	X	X	
7. P yells at or slaps C					X	
8. P plays/sings with C					X	
9. P gets upset with spouse at C's mealtimes	X					
10. P agrees with spouse regarding the amount C should eat	X					
C. Child Behavioral Characteristic						
1a. C watches television while eating	X		X			
1b. C brings toys/books to the table			X	X	X	
2. C enjoys eating	X		X			
3. C asks for food he shouldn't have	X		X			
4. C eats quickly						
5. C takes food between meals without asking	X		X			
6. C eats foods of varied tastes	X		X			
7. C lets foods sit in his mouth	X		X			X
8. C's meal time behavior upsets spouse	X		X			
9. C's meat time behavior upsets siblings	X		X			

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10. C eats when upset	X					
11. C says he's hungry	X					
12. C hides food	X		X			
13. C is alert and attends during meal times				X	X	
14. C looks at P during meal times			X	X	X	
15. C helps clear table	X		X			
16. C interrupts P's conversations during mealtimes	X		X			
17. C Pica (eats nonfood items)		X				
18. C on bottle after 24 months		X	X			
19. C refuses solids	X		X		X	X
20. C refuses liquids	X		X	X	X	
22. Relatives complain about C's eating	X		X			
23.						
D. Parent/Child Interactions						
1. P feeds even if C doesn't want to eat	X		X			
2. P feels child eats enough	X	X	X			
3. P finds meals stressful	X		X			
4. P gets upset when C doesn't eat	X					
5. P lets C have between meal snacks	X					
6. P gets upset when thinks about C's mealtime behaviors	X	X				
7. P lets C chose at meals between served foods	X					
8. P problems positioning C for feeding		X	X		X	X

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E. Functional Feeding/Eating Skills						
1. C's eating takes over 45 minutes/mealtime	X	X	X			
2. Age appropriate self-feeding by C	X					
3. C gags at mealtimes	X	X	X		X	
4. C vomits at mealtimes	X	X	X		X	
5. C chokes at mealtimes	X	X	X			
6. C coughs at mealtimes						X
7. C swallows without problems		X			X	
8. C gets nausea during mealtimes		X				
9. C has diarrhea		X				
10. C has constipation		X				
11. C is tube fed		X	X		X	
12. C takes less than 16 oz. Of formula/day		X				
13. C takes more than 32 oz. of formula/day		X				
14. C demonstrates nasal regurgitation			X			
15. C looks away from P during mealtimes			X	X	X	
16. C receives special formula		X	X			X
17. C's weight for height greater than 95th percentile		X				
18. C's height for age less than 5th percentile		X				X
19. C's weight for age less than 5th percentile		X	X			X
20. C's weight for height less than 5th percentile		X	X			X
21. Appears overweight		X				

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22. Appears underweight		X	X			X
23. Head circumference less than 5th percentile		X				X
24. Reported weight loss or lack of weight gain		X	X			X
25. History of NICU stay			X			
26. History of tube feeding			X			
27. History of force feeding			X			
28. Known diagnosis related to feeding risk		X	X			X
29. Known gastrointestinal problem		X	X			X
30. Known Craniofacial problem						
31. Medication which may effect feeding		X	X			X
32. Food allergy		X	X			
33. C's neck is extended backwards more than 90 degrees			X	X		X
34. C shows abnormal reflexes				X		
35. C shows abnormal oral reflexes				X		
36. C shows abnormal oral muscle tone			X			X
37. C demonstrates lips closure with no leakage of food or liquid			X			X

Piloting was done with five parents who fit the criteria for research subjects. Changes to the interview were made after each pilot interview. Modifications were also facilitated through input from content experts including all dissertation committee members and the doctoral research seminar group of Boston University Sargent School, Occupational Therapy Program. Based on the researcher's experience during piloting, comments made

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by parents during piloting, and related discussions with resource experts, the Feeding Questionnaire was modified. Questions were added to the Feeding Questionnaire related to the primary feeder's comfort with letting other people feed his/her child, satisfaction with support received with feeding, and overall feeding satisfaction.

In its final form, the Feeding Questionnaire has four sections. Section A asks open-ended questions about general feeding concerns, feeding in relation to other child care tasks, and time taken for feeding.

In Section B, parents rate the frequency of their child's feeding problem behaviors. Items are rated based on their frequency of occurrence during feeding. Rating is done using a five-point scale. Parents rate the occurrence of an item: 0 if it never occurs, 1 if up to 25% of the time, 2 if up to 50% of the time, 3 if up to 75% of the time, and 4 if more than 75% of the time. In addition, for each behavior that occurs (given a frequency rating of 1 to 4) parents rate how frustrating they find the behavior. Frustration is rated on a continuum from 0-Not frustrating to 4-Extremely frustrating. The scales for scoring Section B and C were given to the parent on an index card during the appropriate section of the interview.

For each item, three scores are identified 1) Frequency, 2) Frustration, and 3) Problem Intensity 1. Problem Intensity 1 is calculated as Frequency X Frustration. If a problem frequency was 0 (the problem never occurred), problem frustration was not scored but problem intensity received a score of 0. However, if there was a problem frequency of 1 to 4, but data for problem frustration was missing, problem intensity was not calculated and appears as missing data.

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In section C, parents rate the frequency of occurrence of age appropriate child feeding abilities. Parents rate the occurrence of the positive feeding behaviors as: 0 if the positive behavior never occurs, 1 if up to 25% of the time, 2 if up to 50% of the time, 3 if up to 75% of the time, and 4 if more than 75% of the time.

Section D includes open-ended questions followed by sale scored questions. These open-ended questions address parents' overall experience of feeding and the adequacy of the support they receive. The interview includes specific probes regarding the reasons behind parent answers (included in bold print on the Feeding Questionnaire-Interviewer Form, Appendix E). Scale scored questions then ask parents to rate their overall satisfaction with feeding and the support they receive. These last questions were developed based on the scale scored questions involving overall parenting satisfaction included in the demographics section of the Parenting Stress Index but were modified to specifically address feeding. Responses to the interview were recorded on the Feeding Questionnaire-Interviewer Form.

2d. Family Demographics and Medical History Form: Developmental and medical information was gathered from information in the Birth-to-Three records using the Family Demographics and Medical History Form (Appendix F). Decisions on relevant demographic and medical information to include were based on a review of the feeding literature (Pridham, Brown, & Schroeder, 1998; Welch, 1996). Developmental areas assessed in the Birth-to-Three record include Physical Development-gross motor and fine motor, Cognitive Development, Personal/Social Skills, Self-Help/Adaptive Skills, and Communication Skills-receptive and expressive language. Developmental level is reported in the Birth-to-Three record based on standardized tests that provide standard deviation

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scores for each area of development. Testing is individualized based on the characteristics of the child. Evaluations from the Birth-to-Three record included one or more of the following assessments: parent report, clinical observations, the Battelle Developmental Inventory (BDI), Mullen Scales of Early Learning (MSEL), Peabody Gross Motor Assessment Scales, Pre-School Language Scale-3 (PLS-3), Infant-Toddler Developmental Assessment (IDA), and/or the Goldman-Fristoe Test of Articulation (GFTA).

2e. Parenting Stress Index/Short-Form (PSI/SF): The Parenting Stress Index/Short-Form (Abidin, 1995b) was used to assess parental perceptions regarding the stress of parenting their disabled child. The PSI/SF includes 36 questions from the full length PSI. The PSI measures stressors related to parenting and being a parent (Crowley, 1995). Scoring followed the standard procedures for scoring the PSI/SF. Two tests that had a single item missing were scored through assigning the missing item the mean score for its subscale as specified in the PSI manual (Abidin, 1995a).

The Parenting Stress Index/Short-Form (PSI/SF) is a self-report measure asking parents to give their initial responses to various items related to parenting the child they are most concerned about. For this research, parents were asked to respond related to their child with developmental delays and feeding problems. The PSI/SF includes 36 items rated using a five point Likert type scale, with most items asking for a response ranging from Strongly Agree to Strongly Disagree. It takes approximately ten minutes for parents to complete (Abidin, 1995a).

There are three subscale scores and a total score derived from the PSI/SF. The PSI/SF subscales are Parental Distress (PD), the Parent-Child Dysfunctional Interaction (P-CDI), and the Difficult Child (DC). Also included is a Defensive Responding (DR) scale that

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assesses if parents are trying to present an image that they do not have the normal emotional stresses associated with parenting. A DR raw score below 10 may suggest the parent is approaching the questionnaire with a strong bias toward presenting a favorable impression and minimizing indications of parenting stress (Abidin, 1995a).

The Parental Distress subscale assesses stress related to the parent role " . . . as a function of personal factors that are directly related to parenting" (Abidin, 1995a, p.55). Component stresses of the PD subscale include perceived parental incompetence, lacking social support, conflict with the other parent, and depression (a known correlate of dysfunctional parenting). Statements include: "I feel trapped by my responsibilities as a parent" and "Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend)" (Abidin, 1995b). The Parental Distress subscale assesses feelings of sadness related to the parental role. Choosing *Strongly Agree* results in the highest possible score for an item (Abidin, 1995a). A score of above 36 in Parental Distress (above the 90th percentile) is considered indicative of the need for intervention, which could include parent counseling or parent support groups (Cowen, 1998).

The Parent-Child Dysfunctional Interaction (P-CDI) subscale focuses on the parent's stresses related to interactions with his/her child and the child not meeting parental expectations. Statements include "My child smiles at me much less than I expected" and "Sometimes my child does things that bother me just to be mean" (Abidin, 1995b). The Parent-Child Dysfunctional Interaction subscale addresses the parent's experience of interacting with the child. The highest score for an item is given to parents who strongly agree with the statements. A mean score of 28 or higher on this subscale reflects a

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parent's feelings that the child is a negative element in their life, and rapid intervention is indicated for these parents (Cowen, 1998).

The Difficult Child (DC) subscale focuses on behavioral characteristics of the child that determine how difficult the child is to manage. Statements include "My child seems to cry or fuss more often than most children" and "My child's sleeping or eating schedule was much harder to establish than I expected" (Abidin, 1995b). These questions on the Difficult Child subscale assess the parent's view of their child's problems and the difficulty of meeting their child's needs. A response of Strongly Agree results in the highest possible score for an item (Abidin, 1995a). Abidin (1995a) states that parents with high scores on the Difficult Child (DC) subscale " . . . Regardless of the cause of the problems . . . usually need professional assistance" (p.56). A score greater than 36 (above the 90th percentile) reflects a parent's feelings that the child is a negative part of the parent's life and indicates the need for rapid intervention (Cowen, 1998).

The Total Stress score is a summation of the subscale scores, and indicates the overall level of stress experienced within the parent role (Abidin, 1995b). Abidin (1995b) describes parents who obtain a Total Stress score above a raw score of 90 (at or above the 90th percentile) as experiencing clinically significant levels of stress. Referrals related to a total raw score of 90 or higher usually lead to individualized treatment to promote family coping and a safe environment for the child (Cowen, 1998).

The test-retest reliability and alpha for the total score of the PSI Short-Form are .84 and .91 respectively. Subscale reliability and alpha for PD are .85 and .87, for P-CDI .68 and .87, and for DC .78 and .85 (Abidin, 1995b). No data on reliability of the short form are available specific to young children with developmental disabilities. However,

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Crowley (1995) has documented similar levels of reliability for the parents of young children with developmental disabilities using the full length PSI. Correlations between the PSI/SF and full length PSI scores indicate that the short-form has comparable reliability to the full length PSI (Abidin, 1995a).

No data on validity of the short form are available specific to young children with developmental disabilities. However, several studies with the full length PSI have demonstrated concurrent and construct validity, as well as discriminate validity for families of children with various physical and mental disabilities (Innocenti et al., 1992). DeMaso et al. (1990) in a study of children with congenital heart disease found scores on the PSI to be strongly correlated with child adjustment scores on the Child Behavior Checklist.

3. Procedures

3a. Contacting Subjects: The following steps were followed in obtaining the sample: 1) Service providers from Birth-to-Three Program agencies were contacted by this researcher 2) Permission to request volunteers for the study was obtained from agency directors 3) Direct service providers were briefed on the study and given written materials and consent forms to distribute to families who met the study criteria 4) Direct service providers obtained signed consent forms from families who volunteered to participate in the study 5) Direct service providers provided the researcher with prospective subjects', names and phone numbers of these, and 6) The researcher contacted prospective subjects to arrange for an interview at their convenience.

After 21 subjects were obtained through the above procedure, the researcher was unable to obtain additional subjects through this method. Ten additional subjects were then recruited through the Internet (e.g. Family Voices, Dysphagia, and G-tube listserv

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sites), Down Syndrome Congress newsletter, referral from pediatric occupational therapists, and referral from parents of children with developmental disabilities.

Twenty-four of the 31 interviews were done in the child's home at a time convenient to the parents. Two parents were interviewed at work during their lunch hour at their request. The remaining 5 interviews were done by phone, 4 because the parents lived out of state and one at the specific request of the family. Telephone interviews were done only after no more subjects could be recruited for in-person interviews.

For eight of the 31 subjects the PSI-Short Form was presented by the researcher verbally (rather than done through parents filling out the form), with the parents' selections marked by the researcher. The eight verbal presentations of the PSI-SF included five parents who were interviewed by telephone, two parents interviewed in person who were unable to read, and one parent interviewed in person who chose not to stop holding her newborn infant.

3b. Steps in interview, time required, and order: The following steps were followed with the 26 parents who were interviewed in person: 1) Before the interview, a signed Informed Consent Form (Appendix H or Appendix I) was obtained from the parent and demographic information about the family was collected from their Birth-to-Three chart. 2) The interview began with the demographic questions, followed by the Feeding Questionnaire. 3) After the Feeding Questionnaire was completed, parents were asked to fill out the Parenting Stress Index/Short-Form and the Information About You Form (the researcher usually played with or fed the child while the parent filled out the PSI/SF). 4) Parents were mailed a Toys R Us gift certificate and a thank you note within two weeks following the interview.

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For the Feeding Questionnaire, questions followed the written format of the Feeding Questionnaire, but were discussed in a conversational way rather than word for word. Items were marked as the parent spoke. Parents were given a copy of the Feeding Questionnaire (Appendix D) to look at while the researcher asked the questions verbally. Ten of the thirty-one interviews were also tape recorded and reviewed for accuracy following the parent visit. No differences in scaled item scoring were found based on the interviews, but direct quotes were taken from the tape recorded interviews for consideration in the impressions section of this dissertation.

For the five parents interviewed by telephone the following steps were followed: 1) Before the interview, the parents were sent a self-addressed stamped envelope by the researcher and asked to fill out and return the Informed Consent Form and send a copy of the child's Birth-to-Three evaluations. 2) The interview was conducted through a telephone call at a time established by e-mail or previous telephone contact to be most convenient for the parent. 3) The Feeding Questionnaire, Demographic Interview, Parenting Stress Index-Short Form, and Information About You Form questions were all completed by phone. Parents were mailed a Toys R Us gift certificate and a thank you note within two weeks following the interview.

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CHAPTER IV

RESULTS

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Introduction

This chapter presents information that answers the research questions of this paper. These questions are addressed sequentially. For Question 1, Difficult or frustrating aspects of feeding, responses to the open-ended questions are reported first. Responses to the scale questions are then described, specifying the percentage of parents rating problem frequency as 3 or 4 (e.g. problem occurs more than half the time), and the percentage rating problem frustration as 3 or 4 (on a continuum with 4 = Extremely Frustrating).

Next, problem intensity is calculated as the product of frequency and frustration. The means and standard deviations are given. Two types of problem intensity scores are provided, which describe different aspects of parents' frustration related to feeding. Problem Intensity 1 assigns a score of 0 if the problem does not occur (e.g., problem frequency is 0). Problem Intensity 2 omits responses in which problem frequency was rated as 0. For Question 2, Rewarding aspects of feeding, the open-ended and scale scored questions related to rewarding feeding behaviors are considered. For the scale questions, the percent of parents rating positive behavior frequency as 3 or 4 (e.g. positive behavior occurs more than half the time) is described.

For Question 3, Parent's overall satisfaction with feeding, the results from the four scale questions are described. In Section C, parents rate the frequency of occurrence of age appropriate child feeding abilities. Ratings are done using the same frequency scale described for Section B (see Appendix D).

For Question 4, Relationship of parenting stress to parents' perceptions of feeding costs, rewards, and overall feeding satisfaction, the correlations between parenting stress and

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parents' perceptions of feeding are described using the Parenting Stress Index/Short-Form (PSI/SF). Parenting stress on the PSI/SF is reported by providing raw scores for Total Stress and the three subdomainsof Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. First, the PSI/SF Total Stress and subdomain raw scores are reported for the parents in this study. Then the correlations between the total stress and three subdomain raw scores are reported.

Following this description of parenting stress, relationships between the demographic variables and parenting stress are described. The relationship between these major demographic factors and parenting stress describes the context in which parent's feeding perceptions occur.

Consideration is then given to the relationship between parenting stress and parents' perceived feeding costs. Individual parent's total problem frequency, frustration, and problem intensity 1 scores are described, and each of these summary scores is correlated with parenting stress. Because no significant relationships were found between the summary scores and parenting stress, as a next step it was decided to consider the feeding problem behaviors individually.

The frequency, frustration, and intensity scores for each of the 16 problematic feeding behaviors are correlated with the PSI/SF Total Stress and subdomain scores. Significant correlations between feeding behavior scores and parenting stress are described, while the high degree of error introduced by the large number of correlations that were considered is noted.

Next, the correlations between parenting stress and positive feeding behaviors are considered. First, the relationship between total scores for positive feeding behaviors and

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parenting stress is described. Because no significant relationship between these total scores and parenting stress was found, correlations between parents' scores on the items that compose the positive feeding behavior totals were considered in order to assess internal constancy for this measure. Because there were no significant correlations between the scores on specific items and the positive feeding behavior total, the relationship between specific positive feeding problem behaviors and parenting stress is considered. One highly significant correlation between a specific feeding behavior and parenting stress is described. However, the error introduced by the high number of correlations considered also is noted.

In Question 5, Regarding parents' perceptions of feeding treatment, parents' descriptions of three factors related to Birth-to-Three feeding intervention are described. First, the relationship between the parents' level of parenting stress and whether or not their child received feeding intervention is considered. Second, parents' perceptions of the impact of feeding intervention are categorized and correlated with parenting stress. Third, parents' perceptions of feeding intervention are categorized regarding the degree of match between the parents' feeding goals and the goals in the child's IFSP (Individual Family Service Plan; goals section of the child's Birth-to-Three record). Then the relationship between parenting stress scores and the degree to which parent and IFSP feeding goals matched is described.

Question 1: What components of feeding do parents of toddlers/preschoolers who have developmental and eating problems describe as difficult and frustrating?

1A. Open-ended Questions

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Parents' responses to the open-ended questions related to feeding problems were reviewed to answer research question 1. Parents' responses were categorized for the questions regarding parents' greatest feeding concerns, what they find most frustrating in feeding, and areas of feeding they need help with. Parents gave one to four responses to each question, and the percentage of parents mentioning each category was calculated (see Appendix I for reliability details).

In describing their greatest concerns in feeding their child, the child getting adequate nutrition, vitamins, calories, and/or liquid by mouth was by far the most frequently mentioned concern (Table 5). This category was mentioned by approximately two-fifths of the parents, and far exceeded all other responses. The next most frequently mentioned categories, were the limited diet parents could offer (11%); self-feeding , utensil, and cup use(9%); and their child refusing to eat (9%).

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Table 5

Rank Order of Greatest Feeding Concerns

Greatest Concerns Category	Frequency	Percent
1.Child getting adequate nutrition/vitamins/calories/liquid orally	17	37.8
2.Limited diet parent can offer	5	11.1
3.Self-feeding, utensils, and cup use	4	8.8
4.Child refuses to eat	4	8.8
5.Chewing/swallowing/oral-motor ability	3	6.6
6.Ambiguous/ Other	2	4.4
7.Feeding tube concerns	2	4.4
8.Vomiting or reflux	2	4.4
9.Persistence of eating problems	2	4.4
10.Mealtimes are unpleasant	2	4.4
11.Oral sensory over-sensitivity	1	2.2
12.Won't eat too much fat	1	2.2

In describing the most frustrating aspects of feeding their child, refusing the food that was offered was most commonly mentioned. Refusing the food offered was mentioned by nearly a third of the parents (Table 6). The next most frequently mentioned category was their child's unhappy and/or negative behaviors, described by approximately one quarter of the parents. Approximate one tenth of the parents mentioned oral-motor problems, and the child not communicating food preferences.

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Table 6

Rank Order of Greatest Frustrations in Feeding

Most frustrating in feeding	Frequencies	Percent
1.Refuses food offered	15	30.6
2.Unhappy and/or negative behaviors	11	22.4
3.Oral motor problems (taking food with lips. chewing, swallowing)	6	12.2
4.Does not communicate food wants/ doesn't want	4	8.2
5.Need to coerce/distract child so eats	3	6.1
6.Child not taking enough food	3	6.1
7.Limited types of foods can give Child	3	6.1
8.Child stuffs mouth with food	1	2
9.Special feeding equipment	1	2
10.Too time consuming to feed	1	2
11. Ambiguous/other	1	2

Regarding the aspects of feeding they needed help with, approximately one fifth of the parents reported needing help with their child accepting a variety of foods and/or new foods, and one-fifth described needing help with improving oral-motor skills (Table 7). The next most frequently mentioned needs for feeding assistance, each mentioned by approximately one tenth of the parents, were evaluating and progressing their child's feeding development, suggestions regarding types of food to offer, interpersonal and/or interactional feeding strategies, and other people doing the feeding and/or cleanup.

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Table 7

Rank Order of Feeding Areas with which Parents Indicated Needing Help

Category of Feeding Areas Parents Need Help With	Frequency	Percent
1.Child accepting a variety of foods and/or new foods	9	18.8
2.Improving oral-motor skills (chewing, positioning for eating, swallowing, tongue/lip use)	9	18.8
3.Evaluating and progressing Child's feeding development	4	8.3
4.Suggestions regarding types of foods to give	4	8.3
5.Interpersonal and/or interactional eating strategies	4	8.3
6.Assistance with doing the actual feeding and/or cleanup	4	8.3
7.Techniques to improve self-feeding skills	3	6.3
8.Ambiguus/other	3	6.3
9.Integrating strategies to improve feeding skills into the families routines	2	4.2
10.Many or all aspects of feeding	2	4.2
11.Tube feeding techniques	2	4.2
12.Nothing	2	4.2

A second method also was used in categorizing parents' needs for assistance with feeding. This second categorization focused on the types of coping resources needed by parents (see Appendix I for specifics on reliability). Parents' responses fell into three categories: Feeding techniques/strategies, social support, and no support. The number and percent of parents identifying the need for help with each of these categories is presented in Table 8. In this second categorization of needs for feeding assistance, help with feeding techniques/strategies was mentioned by most of the parents. The next most commonly mentioned category was social support, mentioned by approximately one fifth of the parents. The least frequently mentioned category was not needing support with feeding, mentioned by less than ten percent of the parents.

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Table 8

Method 2 Areas of Feeding Parents Indicated Needing Help With: Frequency & Percent (Total N=30)

Mentioned as Category Parent Needed Help With	Frequency	Percent
Feeding Techniques/Strategies Only	27	90.0
Social Support	6	20.0
Both Feeding Techniques/Strategies and Social Support Mentioned	5	16.7
No support needed	2	6.7

1B. Scale Scored Questions

Following analyses of the open-ended questions, responses to the scaled items related to feeding concerns were assessed. The feeding questionnaire listed problems related to feeding and parents rated how frequently their child demonstrated the problem. The parents reported that most of their child's problematic feeding behaviors occurred less than three-quarters of the time (Table J1, Appendix J). As a next step, ratings of 3 and 4 were combined to determine feeding problems that occurred more than fifty percent of the time (Table 9). For problematic feeding behaviors occurring more than fifty percent of the time, over half of the families mentioned refusing age appropriate food textures. The next most common problem, their child refusing eating enough, was mentioned by just under half the parents. Approximately one third reported their child needed distractions to eat and one third reported their child spit out food. Responses to the questions about feeding concerns also identified behaviors that did not present problems for this group of parents.

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Table 9

Rank order of Feeding Problems Occurring More than Half the Time

Feeding Problem	Problem occurs more than half the time (3 or 4)	N
1.Refuses age appropriate food textures	16 (53.3%)	30
2.Refuses eating enough	15 (48.4%)	31
3.Refuses food unless distracted	9 (30.0%)	30
4. Spits out food	9 (30.0%)	30

For each problem that occurred, the parents also rated the degree of frustration they experienced while the problem was occurring. Parents were asked to rate the level of frustration they experienced from 0 Not Frustrating to 4 Extremely Frustrating. Parents' ratings of their degree of frustration for each feeding problem are presented in Appendix J2.

The valid percent of parents rating each problem as causing high frustration was assessed by combining frustration ratings of 3 and 4 for each feeding problem (Table 10). The problem most often rated as high frustration (e.g. rated 3 or 4) was refuses eating enough, which was identified by four-fifths of the parents as highly frustrating. The next most commonly described high frustration behaviors were: crying, described by nearly four-fifths of the parents; refusing to drink enough, identified by slightly under three-quarters of the parents; and lacking adequate posture for eating and choking on food, which both were identified by three-fifths of the parents.

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Table 10

Rank Order of High Frustration Feeding Problems

Feeding Problem	N (Number who identified problem)	3 or 4
1.Refuses eating enough	21	17 (80.9%)
2.Crying during meals	19	15 (79%)
3.Refuses drinking enough	11	8 (72.7%)
4. Lacking postural control for eating	10	6 (60%)
5.Choking on food	22	13 (59.0%)

Problem Intensity 1 was used to describe the parents' overall dissatisfaction related to each feeding problem (Table J3 and Table 11). Scores had a possible range of 0 to 16. The mean problem intensity score was highest for refusing eating enough ($M = 7.20$, $SD = 7.92$, Table 13). Other categories with a mean intensity score over 4, in rank order, were refusing age appropriate textures of food ($M = 6.13$, $SD = 6.06$), spitting out food ($M = 4.98$, $SD = 6.20$), and crying during meals ($M = 4.06$, $SD = 5.13$). However, the mean problem intensity scores in Tables 13 and 14 may not be representative of the sample since the standard deviation scores were so proportionally high. Fourteen of the 16 problem intensity scores had a standard deviation that exceeded the mean, and 4 of the standard deviation scores were more than twice as large as the mean.

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Table 11

Rank Order of Problem Intensity 1:
Means & Standard Deviations

Feeding Problem	Mean	SD
1.Refuses eating enough	7.20	6.92
2.Refuses age appropriate food textures	6.13	6.06
3.Spits out food	4.98	6.20
4.Crying during meals	4.06	5.13
5.Choking on food	3.96	5.23
6. Takes too long to feed	3.96	5.23

Because the high standard deviation scores in Problem Intensity 1 suggested that the mean problem intensity scores may have been influenced primarily by ratings of 0 for problem occurrence (resulting in a product of 0 for the problem intensity score), a second analysis of problem frustration was done excluding cases for which problem occurrence was rated 0. This second analysis considered the degree of frustration experienced when feeding problems occurred (Table J4 and Table 12) .

Using this Problem Intensity 2 analysis, both eating enough and drinking enough emerged with the highest mean problem intensity scores (Table 12). Refusing age appropriate food textures (M = 8.76, SD = 5.38) and spitting out food (M = 8.06, SD = 6.10) continued to have high mean problem intensity scores. Lacking adequate postural control for eating was fifth in rank-order with a mean of 7.90 (SD = 5.04), compared to a mean of 2.63 (SD = 4.72) in the previous analysis, suggesting that when they occurred postural problems resulted in high overall frustration.

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Table 12

Rank Order of Problem Intensity 2 Means:
Means & Standard Deviations

Feeding Problem	Mean	*SD*
1. Refuses drinking enough	9.64	*6.74*
2. Refuses eating enough	9.62	*6.36*
3. Refuses age appropriate food textures	8.76	*5.38*
4. Spits out food	8.06	*6.10*
5.Lacking postural control for eating well	7.90	*5.04*

Question 2: What components of feeding do parents of toddlers/preschoolers who have identified developmental and eating problems describe as rewarding?

2A. Open-ended Questions

A single open-ended question was used to consider the feeding behavior parents' described as rewarding. The positive feeding behaviors mentioned by the parents are presented in Table 13 (see Appendix I for reliability information). The child accepts, enjoys, and/or takes new food by mouth was by far the aspect of feeding most commonly described as rewarding. This behavior was mentioned as rewarding by approximately half the families, and mentioned by more than twice as many families as any other feeding behavior. The next most frequently mentioned feeding reward was Completion of functional oral eating which was described by approximately one fifth of the families. The child demonstrating progress in eating was the third most mentioned behavior. Use of a strategy that works and a sense of nurturing interactions with the child were tied as the fourth most mentioned rewarding feeding behaviors.

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Table 13

Rank Order of Rewarding Feeding Behaviors Reported

Feeding Rewards	N	Percent
Child accepts, enjoys, and/or takes new food by mouth	23	48.9%
Completion of functional oral eating	8	17.0%
Child demonstrates progress in eating	6	12.8%
Use of strategy that works	3	6.4%
Sense of interaction with and/or nurturing of C	3	6.4%
Child participates in self-feeding and/or uses utensils	2	4.2%
Child's weight gain	1	2.1%
Other/ambiguous statements	1	2.1%

2B. Scale Scored Questions

For positive feeding behaviors, only the frequency of occurrence of behaviors was considered. Parents' ratings of the frequency of occurrence of positive feeding behaviors are presented in Table J5. The percentage of parents reporting that the positive feeding behaviors occurred more than half the time are presented in Table 14. Of these the most commonly reported positive feeding behavior that occurred more than half the time was keeping food in the mouth, which was reported by more than four-fifths of the parents. The next most commonly mentioned positive feeding behaviors which occurred more than half the time (all reported by at least half the parents) were accepting the touch of the spoon; sitting long enough to complete the meal; and opening the mouth for the spoon. These commonly reported positive feeding behaviors reflect feeding skills that occur earliest in normal development (Glass & Wolf, 1998).

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Table 14

Positive Feeding Behaviors Occurring More than Half the Time

Positive Feeding Behaviors	N	Percent
Keeping food in mouth	25	80.7%
Accepting touch of spoon	22	71.0%
Sitting long enough to eat	21	67.8%
Opens mouth for spoon	18	59.7%
Lips take food off spoon	17	58.6%
Accepting wiping of face	15	50%

Question 3: How do parents of toddlers/preschoolers who have identified developmental and eating problems rate their overall satisfaction with feeding?

Four rating scales were used to describe parents' overall satisfaction with feeding. These included three items rating level of satisfaction, and one item involving ranking feeding among other child-care tasks. For the three satisfaction level rating items parents rated their overall satisfaction with various aspects of feeding on a scale from 1-Very Unsatisfied to 5-Very Satisfied (Tables 15-18).

Table 15

Overall Satisfaction with the Experience of Feeding

Rating	Frequency	Valid Percent
1-Very Unsatisfied	5	17
2	4	14
3	8	28
4	9	31
5-Very Satisfied	3	10

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The parents' ratings of their overall satisfaction with feeding their child indicated considerable diversity among the parents in this area. As indicated in Table 15, while 17% were Very Satisfied, 10% were Very Unsatisfied. The mean of 3.03 (SD = 1.27) was close to midpoint between the ratings of very satisfied and very unsatisfied.

The parent's ratings of overall satisfaction with the amount of feeding support they received also indicated great diversity across the parents. More than half the parents rated their overall satisfaction with their amount of feeding support positively (with scores of 4 or 5), while nearly two fifths gave negative ratings of feeding support satisfaction (scores of 1 or 2). The mean rating was 3.66 (SD = 1.34).

Table 16

Overall Satisfaction with Feeding Support

Rating	Frequency	Valid Percent
1-Very Unsatisfied	3	10
2	2	7
3	6	21
4	8	28
5-Very Satisfied	10	35

Parents' overall satisfaction with the balance they had between feeding their child, other family responsibilities, personal interests, and work responsibilities also indicated strong diversity among the parents. While approximately one-fifth of the parents indicated the lowest possible satisfaction rating, one-fifth indicated the highest possible rating (Table 17). The mean of 2.98 (SD = 1.44) was close to midpoint between the ratings of Very Unsatisfied and Very Satisfied.

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Table 17

Overall Satisfaction with Balance Between Feeding and Other Responsibilities

Rating	Frequency	Valid Percent
1-Very Unsatisfied	7	23
2	3	10
3	9	30
4	5	17
5-Very Satisfied	6	20

Parents ranked feeding and their other child care tasks in terms of enjoyability (Table 18). Parents' ranking of feeding as a child-care task showed some variability, but was the only measure of overall feeding for which the ratings were highly unfavorable. Nearly half the parents ranked feeding as their least enjoyable child-care task, while less than one-fifth of parents ranked feeding above the middle level in enjoyability.

Table 18

Overall Ranking of Feeding Favorability

Ranking	Frequency	Valid Percent
1-Least favorite	15	48
2-Among the less favorable	4	13
3-Middle	7	26
4-Among the more favorable	4	13
5-Most favorite	1	3

Question 4: How do parents' perceptions of feeding costs, rewards, and overall satisfaction with feeding relate to parenting stress?

The relationship between parents' perceptions of feeding and parenting stress was assessed using the Parenting Stress Index/Short Form (PSI/SF). The PSI/SF includes the

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Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC) subscales and a Total Stress score (which is the sum of scores of the three subscales). The PSI/SF also includes a Defensive Responding (DR) scale to assess if parent's scores' may be biased because they are trying to present themselves in a positive manner.

4A. PSI/SF Scores

Scores on the PSI/SF for the 31 parents in the sample are presented in Table 19. Scores for the Parental Distress subscale had a mean of 31.58, ranging from 17 to 50. The mean for Parent-Child Dysfunctional Interaction was 24.23, ranging from 13 to 35, and the mean for the Difficult Child subscale was 33.29, ranging from 16 to 52. The Total Stress score had a mean of 89.10, with raw scores ranging from 53 to 124. Parents in this study had a mean score of 18.9 on the DR scale, ranging from 8 to 29. Only one parent had a DR raw score below 10, a raw score of 8, which suggests that this parent may have been trying to present a positive image by minimizing the stresses associated with parenting.

Scores for the parents on all three subdomains and Total Stress indicated extremely high levels of stress in comparison with the normative sample. Table 19 indicates that the mean scores for the parents on the Difficult Child subscale was at the 85th percentile, Parental Distress at the 80th percentile, and Parent-Child Dysfunctional Interaction at the 75th percentile, all above the expected mean percentile of 50. The mean Total Stress score is at the 88th percentile, just below the 90th percentile level which is considered to be a clinically relevant stress level requiring intervention (Abidin, 1995a).

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Table 19

PSI/SF Total Stress and Subdomain Raw Scores (N = 31)

PSI Section	Mean	Minimum	Maximum	SD	Percentile (Stress Level)
Defensive Responding	18.90	8	29	5.70	
Parental Distress	31.58	17	50	9.54	80th
Parent-Child Dysfunctional Interaction	24.23	13	35	5.51	75th
Difficult Child	33.29	16	52	9.34	85th
Total Stress	89.10	53	124	17.56	88th

The correlations among the subdomain and total stress scores on the PSI/SF are presented in Table 20. The positive correlation between the Difficult Child and Parent-Child Dysfunctional Interaction subdomain was significant at the .01 level, but the Parental Distress subdomain was not significantly correlated with either the Difficult Child or the Parent-Child Dysfunctional Interaction subdomains.

Table 20

Pearson Correlations of PSI/SF Total Stress and Subdomain Raw Scores (N=31).

PSI/SF (Sub)domain	Parental Distress	Parent-Child Dysfunctional Interaction	Difficult Child
Parental Distress	-	.243 (.094)	.171 (.179)
Parent-Child Dysfunctional Interaction	.243 (.094)	-	.428** (.008)
Difficult Child	.171 (.179)	.428** (.008)	-
Total Stress	.710** (.0001)	.673** (.0001)	.759** (.0001)

**Correlation significant at the .01 level

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4B. Relationship between demographic variables and parenting stress

Before assessing the relationship between feeding behaviors and parenting stress, consideration was given to the relationship between stress and specific demographic factors related to feeding that the literature suggests may be related to parenting stress. The relationship between demographic variables and parenting stress was assessed through the correlation (at the .05 level) of demographic variables with PSI/SF Total Stress and subdomain raw scores (Parental Distress, Difficult Child, and Parent-Child Dysfunctional Interaction).

The negative correlation between the primary feeder's education level and PSI/SF Total Stress and subdomain raw scores were not significant. However, the negative correlation between the primary feeder's education level and the Parent-Child Dysfunctional Interaction subdomain approached significance at the .056 level ($r = -.292$, $p = .056$). The relationship between annual household income and parenting stress was also considered. Because the literature supports a negative correlation between socio-economic status and parenting stress on the PSI/SF, one-tailed significance was assessed. The negative correlations between annual household income and parenting stress on the PSI/SF were not significant.

The next demographic consideration was whether there were significant differences in parenting stress related to child factors of diagnosis and tube feeding status. An independent samples t-test was done to assess differences in PSI Total Stress raw scores between parents of children in the Pervasive Developmental Disorder and Cerebral Palsy diagnostic category groups. No significant difference was found (PDD: $M = 88.17$, SD

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= 22.43, N = 6; CP: M = 86.67, SD =1 2.87, N=12; p = .88). An independent samples t-test also showed no significant differences in PSI Total Stress raw scores between parents of children receiving tube feeding and not receiving tube feeding (Tube: M = 93.75; SD = 20.86; N = 8; No Tube: M = 87.96, SD = 16.78, N = 23; p = .44).

4C. Relationship between Feeding Costs and Parenting Stress

The considerable time required for feeding young children with developmental and eating problems is a frequently mentioned feeding cost. Factors related to the responsibilities of the primary feeder were correlated (for 2-tailed significance at the .05 level) with raw scores on PSI/SF total stress and three subdomain raw scores. One significant positive correlation was found between the percent of feeding done by the primary feeder and parenting stress on the Parent-Child Dysfunctional Interaction subdomain (r = .404, p = .027). There was no significant correlation between the average total time required daily for feeding (all eating and drinking assistance and/or direct supervision including tube feeding done by all feeders) and PSI/SF scores. There was also no significant correlation between hours worked by the primary feeder and parenting stress.

For each parent total scores for problem frequency, frustration, and intensity were calculated. The totals were then correlated with the PSI/SF raw scores. No significant correlations were found between these total scores for problem frequency, frustration, or intensity I and the PSI/SF raw scores for total stress or any of the subdomain scores.

Because the total frequency, frustration, and intensity scores were not related to parenting stress, coefficient alpha was calculated to look at the internal consistency for the problem frequency, frustration, and intensity scores, respectively. The problem frequency

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items had a coefficient alpha of .61 (cases = 25, items = 16), indicating internal consistency of these scores as a group. Problem frustration items had a coefficient alpha of .47 suggesting they did not correlate well as a group (cases = 20, items = 16). Problem intensity 1 items had a coefficient alpha of .63 (cases = 22, items = 16), indicating moderate to high consistency of these scores as a group.

Because the correlations between parenting stress and the three summary scores described above were not significant, correlations with parenting stress were calculated for the individual items. Thus, a separate correlation for each measure of parenting stress was calculated for each of the questions concerning problem frequency, each of the questions concerning frustration, and each of the questions concerning intensity. The relationship between each of these feeding behavior ratings and parenting stress on the PSI/SF Total Stress and subdomains was assessed (Table 21). Significant positive correlations with parenting stress were found for the following feeding behavior ratings: refusing/resisting age appropriate textures of food, stuffing food, stuffing food frustration, and stuffing food intensity.

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Table 21

Significant Relationships between Problem Feeding Behaviors & PSI/SF Raw Scores

Feeding Behaviors	Pearson Correlation	PSI/SF (Sub)domain	2-tailed Significance	N
Refuse/resist age appropriate textures of food	.464	DC	.010	30
Stuffs food	.542	PD	.002	31
	.512	DC	.003	
	.592	Total Stress	.0001*	
Stuffs food Frustration	.784	PD	.004	11
	.748	P-CDI	.008	
Stuffs food Intensity	.585	PD	.001*	30
	.595	Total Stress	.001*	

* Indicates a significance level of .001 or .0001, all other correlation .01

In these analyses a high number of correlations was assessed. The correlations of the individual feeding problem frequency, frustration, and problem intensity 1 scores with the PSI/SF Total Stress and 3 subdomain raw scores involved a total of 192 correlations. The high number of correlations done introduced a high probability of error (at the .01 significance level used, 2 significant correlations would be expected to occur by chance). As a result, caution must be noted in interpreting these results.

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4D. Relationship between feeding rewards and parenting stress

The mean summary score for parents' perceptions of positive feeding behaviors was 20.6 with a standard deviation of 5.7. There were no significant correlations at the .05 level between the total positive behavior sum and the PSI/SF Total Stress or subdomain raw scores.

Because the total positive feeding behavior score was not related to parenting stress, coefficient alpha was calculated to consider the internal consistency of the positive feeding behavior items. Scores on the positive feeding behavior items had a coefficient alpha of .47, suggesting they did not correlate well as a group (cases=20, items=16).

Because the positive feeding behavior scores had low internal consistency and no significant relationship with parenting stress as a group, correlations with PSI/SF total stress and subdomain scores were considered for each item (alpha = .01). A very strong negative correlation was found between sitting long enough to complete the meal and the Difficult Child subdomain ($r = -.594$, $p = .0001$, $N = 31$). Despite the substantial number of correlations done between positive feeding behaviors and the PSI/SF raw scores (e.g. 32 total), the strength of the correlation between sitting long enough and the Difficult Child subdomain suggests a real relationship.

4E. Relationship between parent's overall feeding satisfaction and parenting stress

The correlations between measures of overall satisfaction with feeding and PSI/SF total stress and subdomain scores are presented in Table 22. The only significant relationship found was a negative correlation between the PSI/SF Total Stress raw score and overall satisfaction with the experience of feeding (e.g. parents with lower ratings of satisfaction in their overall feeding experience had higher total stress levels). The negative

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relationship between overall satisfaction with feeding support and the PSI/SF Total Stress score approached significance. No significant relationship between PSI/SF total stress or subdomain raw scores was found for ranking of feeding enjoyability, overall satisfaction with feeding support, or overall satisfaction with the balance between feeding and other aspects of the feeder's life.

Table 22

Relationship Between Overall Feeding Satisfaction and Parenting Stress

Overall Satisfaction Measure	Parental Distress	Parent-Child Dysfunctional Interaction	Difficult Child	Total Stress
1. Where would you rank feeding as a child care task in terms of favorability?	-.182 (.406) N=23	.004 (.984) N=23	-.184 (.400) N=23	-.282 (.192) N=23
2. Overall, how satisfied are you with the experience of feeding your child?	-.242 (.205) N=29	-.166 (.390) N=29	-.205) (.286) N=29	**-.374** **(.046)** **N=29**
3. Overall, how satisfied are you with the amount of support you have with feeding?	-.179 (.352) N=29	-.238 (.214) N=29	-.094 (.629) N=29	*-.336* *(.075)* *N=29*
4. How satisfied are you with your balance between other family responsibilities, personal interests and work responsibilities?	-.171 (.365) N=30	.069 (.716) N=29	.079 (.679) N=29	-.103 (.587) N=29

Significant relationship in bold;*relationship approaching significance in italics* 2-tailed

As a next step, the parents' scores on the scale questions regarding overall feeding satisfaction were assessed to determine if there were significant differences between the responses of parents who had children with PDD/Autism and parents who had children with Cerebral Palsy. Comparison of the mean scores of these two groups of parents (2-tailed independent t-test) indicated that the ratings of overall satisfaction with the feeding experience were significantly lower for parents of children with PDD/Autism than for parents of children with Cerebral Palsy (PDD: $\underline{M} = 2$, $\underline{SD} = 1.22$, $\underline{N} = 5$; CP: $\underline{M} = 3.58$. $\underline{SD}$

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= 1.24, N = 12; t = -2.41, p = .029). The mean scale scores on overall feeding satisfaction for parents who had children with PDD was 2.0, indicating parents were Unsatisfied (on a scale from 1-Very Unsatisfied to 5-Very Satisfied), while parents of children with CP had a mean score of 3.6, indicating a satisfaction level slightly above average.

T-tests showed no significant differences between parents of children with CP and PDD/Autism on mean ratings of overall satisfaction with feeding support, satisfaction with the primary feeder's balance between feeding and other personal responsibilities, or ranking of feeding favorability among child care tasks.

Question 5: What are parents' perceptions of the Birth-to-Three Program's feeding intervention?

5A. Relationship between feeding intervention and parenting stress

Consideration of parent's perceptions of feeding intervention began by assessing the percent of families receiving feeding intervention as part of their Birth-to-Three Program. Twenty-three of the parents (76.7%) reported that feeding treatment was part of their child's Birth-to-Three Program, while seven (23.3%) reported that feeding treatment was not included. No significant differences in parental stress were expected on the bases of whether parents received feeding treatment (because of the special circumstances of those not receiving Birth-to-Three feeding treatment e.g., receiving feeding treatment from outside of Birth-to-Three, or no longer needing feeding treatment) this relationship was felt to be important to assess. As expected, an independent samples t-test showed no significant differences in parental stress between parents receiving and not receiving Birth-to-Three feeding treatment.

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5B. Parents' perceptions of the impact of feeding intervention

The second consideration regarding parent's perceptions of feeding intervention was their description of the impact of feeding intervention. These descriptions were categorized using the five response categories in Table 23. A total of twenty-six families (83.9%) responded to this question, with two-fifths of the families reporting feeding intervention had a positive impact only, and one-fifth reporting that feeding intervention had both positive and negative impacts. Parents who described feeding intervention as having both positive and negative impacts described the positive impact of therapists guiding them in strategies to promote their child's feeding skills, and the negative impact of implications from the therapists that parents were not doing enough to help improve their child's feeding skills. Approximately ten percent of parents described feeding intervention as having no impact. Ten percent described treatment as having a negative impact only, and ten percent gave an ambiguous response that could not be categorized.

Table 23

Rank Order Descriptions of the Impact of Feeding Intervention

Response Category	Frequency	Valid Percent
1.Positive Impact Only	11	42.3
2.Both Positive and Negative Impacts	6	23.1
3. No Impact	3	11.5
4. Negative Impact Only	3	11.5
5. Ambiguous	3	11.5

The mean Total Stress scores for parents in each of these groups are presented in Table 24. An independent t-test was used to compare the PSI/SF Total Stress raw scores for

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parents who perceived feeding treatment as having either a positive impact or both positive and negative impacts with parents who perceived feeding as having no impact or a negative impact only. Parents who perceived feeding treatment as having no impact or a negative impact had significantly higher PSI/SF Total Stress raw scores (M = 106.67, SD = 10.99, N = 6) than parents describing feeding treatment as having a positive impact or both positive and negative impacts (M = 87.00, SD = 17.72, N = 17; t =2.530, p = .019).

Table 24

PSI/SF Total Stress Scores for Parents Reporting Varying Treatment Impacts: Number, Mean, and Standard Deviation

Response Category	N	Mean	Standard Deviation
1.Positive Impact Only	11	87.64	16.77
2.Both Positive and Negative Impacts	6	85.83	20.97
3. No Impact	3	101.00	10.15
4. Negative Impact Only	3	112.33	87.64

5C. Degree to which parents' feeding goals match the goals in their child's IFSP

The third step in considering parent's perceptions of Birth-to-Three feeding intervention was determining the degree to which the parent's feeding goals matched the feeding goals in the child's IFSP (Individual Family Service Plan; the Birth-to-Three Program treatment plan). Twenty parents described at least one feeding goal (64.5), while 10 parents (32.3%) also listed a second feeding goal. Assessment was made regarding the degree to which the combined feeding goals in the child's IFSP matched the parents' goals (see Appendix H for reliability information). For both the first and second parent feeding goals, comparisons indicated that most often there was a partial match between parents' goals and the IFSP goals (Table 25 and Table 26).

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Table 25

Match Between Parents First Feeding Goal and IFSP Goals in Rank Order

Degree of Match	Frequency	Valid Percent
1. Did Not Match	4	20
2. Partially Matched	9	45
3. Completely Matched	7	35

Table 26

Match Between Parents Second Feeding Goal and IFSP Goals in Rank Order

Degree of Match	Frequency	Valid Percent
1. Did Not Match	2	20
2. Partially Matched	5	50
3. Completely Matched	3	30

The relationship of the degree of match between the parent and IFSP goals with PSI/SF Total Stress raw scores are described in Table 27 and Table 28. There appeared to be no consistent pattern between the degree of match of parent goals and PSI/SF Total Stress raw scores.

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Table 27

PSI/SF Total Stress Scores of Parents Having Different Levels of Agreement Between Parent Goal 1 and IFSP Goals: Total number, Mean, and Standard Deviation

Degree of Match	N	Mean	Standard Deviation
1. Did Not Match	4	81.50	25.33
2. Partially Matched	9	87.33	15.13
3.Completely Matched	7	101.00	18.34

Table 28

PSI/SF Total Stress Scores of Parents Having Different Levels of Agreement Between Parent Goal 2 and IFSP Goals: Total number, Mean, and Standard Deviation

Degree of Match	N	Mean	Standard Deviation
1. Did Not Match	2	90.50	28.99
2. Partially Matched	5	84.40	22.29
3.Completely Matched	3	81.33	7.51

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CHAPTER V

DISCUSSION

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Introduction

While there are a variety of factors that limit the generalizeability of this study, the findings suggest some new perspectives which may be helpful in considering parents' perceptions of feeding young children with developmental and eating problems. Approximately half of the parents in this study rated feeding as their least enjoyable child care task and had total stress scores at or above the 90th percentile on the PSI/SF, indicating that they were " . . . experiencing clinically significant levels of stress" (Abidin, p.55, 1995a). These and other findings from this study and the literature support the need to increase the emphasis placed on parents' feeding perceptions.

The first section of this chapter addresses findings suggesting the need for a greater emphasis on parents' feeding perceptions in Birth-to-Three programs. The second section discusses parents' perceptions of feeding and feeding intervention. The next sections discuss how the family systems, social exchange, and social comparison theories are helpful for understanding parents' perceptions of feeding young children with developmental and eating problems. Section four discusses the limitations of this study. After acknowledging these limitations, implications of this study for further research are discussed in the fifth section.

Support for a greater emphasis on parents' feeding perceptions

The strongest factor in this study suggesting the need for a greater emphasis by the Birth-to-Three programs on the feeding perceptions of parents with children who have developmental and eating problems is the large number of parents with extremely high parenting stress scores. The parents' mean score of 89 on the Total Stress score of the PSI/SF is important to consider. Parents with a total stress score of over 91 (at or above

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the 90th percentile) are considered to be experiencing clinically relevant levels of stress requiring intervention (Abidin, 1995a).

Specific subdomain stress scores of parents in this study were also found to indicate clinically high levels of stress, with several parents scoring at or above the 95th percentile on subdomain scores which strongly suggest the need for intervention (Abidin, 1995a). Over one quarter of the parents scored at or above the 95th percentile on the Parental Distress subdomain, and approximately one fifth of the parents scored at or above the 95th percentile on the Parent-Child Dysfunctional Interaction and Difficult Child subdomains.

The results of this study are consistent with previous studies indicating that parents of children with developmental and feeding difficulties have significantly higher levels of parenting stress than parents of typical children with no feeding problems (Goldberg et al., 1989; Humphry & Rourk, 1991; Secrist-Mertz et al., 1997; Welch, 1990). However, the mean percentile scores of parents in this study are even higher than the stress percentiles reported in the literature. When considering the high parenting stress scores of parents who have children with developmental and feeding problems, it is unclear whether the greater stress of these parents is related to their child's developmental problems only, or to the fact that their child also has a feeding problem.

In considering the stress of parents who have children with developmental problems, the literature often does not make a clear distinction between children with and without feeding problems (Goldberg et al., 1989). Adams, Gordon, and Spangler (1999) studied 13 parents of developmentally disabled children with and with out feeding problems. They found no significant differences in parenting stress. However, in their study approximately half of the children were between 5 and 17 years old. The older ages of half of these

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children compared to the ages of children in this study may have contributed to the lack of differences found between parents of children with and without feeding problems. The reports by parents in this dissertation that feeding was their least favorite child care task suggests that the feeding component may be a major contributor to stress in parents of young children with developmental and eating problems.

This perception of half the parents in the study that feeding was their least favorite child-care task further suggests that parents may need greater support with feeding from the Birth-to-Three programs. Although parents in this study were particularly likely to perceive feeding as unfavorable because their children had identified feeding problems, the children also had developmental problems that are associated with increased demands in many other child care tasks. The unfavorable ratings of feeding compared with other child care tasks suggests that feeding difficulties may be perceived as particularly problematic by parents of young children with developmental problems.

This finding of a strong dislike for feeding is consistent with the results of two other studies. Pridham et al. (1989) and Reilly and Skuse (1992) both reported that feeding was described as unpleasant by one-third and two-thirds of the parents, respectively. The findings of these studies suggest that parent's of young children with developmental and feeding problems have a strong dislike for feeding as a child-care task.

Further support of the need to focus on parents' feeding perceptions was suggested by the significant negative correlation found in this study between parenting stress and ratings of overall feeding satisfaction. A significant negative correlation was found between Total Stress on the PSI/SF and overall satisfaction with the experience of feeding and the negative correlation between Total Stress and overall satisfaction with the amount of

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support received with feeding approached significance ($p = .075$). This relationship between low overall feeding satisfaction and high parenting stress is consistent with the literature regarding young children with feeding problems (Archer, Rosenbaum, & Streiner, 1990; Douglas & Bryon, 1996; Humphry & Rourk, 1991; Satter, 1992).

It must be noted that due to the lack of established reliability and validity of the Feeding Questionnaire, caution must be used in considering parents' reports in this study regarding both the unfavorability of feeding and the relationship between feeding satisfaction and parenting stress. This caution applies to all of the results based on the Feeding Questionnaire, and consequently all the relationships between items from the Feeding Questionnaire and parenting stress. The lack of reliability and validity of the Feeding Questionnaire will be discussed further in the methodological issues section of this chapter.

However, despite this caution related to the lack of reliability and validity of the Feeding Questionnaire, the findings in this study and the literature suggest that a greater emphasis on parents' feeding perceptions is needed in the Birth-to-Three programs. Despite the salience of feeding problems in the lives of families that include young children with developmental and eating problems, feeding intervention is a related service in Birth-to-Three programs that does not independently qualify children with developmental and eating difficulties for intervention services. The literature indicates that while children's daily eating and mealtime problems can be very stressful for families, these problems often are not addressed because they are functional problems and have no single profession responsible for intervention efforts (Archer, Rosenbaum, & Streiner, 1990). Professionals in the Birth-to-Three programs have identified that they need a better understanding of

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feeding and nutrition problems. For example, in a survey of 34 Connecticut Birth-to-Three programs, 24 of the programs reported they could use additional information or training regarding feeding and nutrition services (Connecticut Birth to Three Nutrition Task Force, 2000).

In conclusion, although it is difficult to determine the specific aspects of having a young child with developmental and eating problems that contribute to high parenting stress, this study along with the existing literature supports the relationship between having a young child with developmental and eating problems and high levels of parenting stress. Given the established relationship between high parenting stress on the PSI/SF and negative developmental outcomes in young children (Cowen, 1998; Deater-Deckard, 1996), it is important to address the negative feeding perceptions of parents who have young children with developmental and eating problems in an effort to reduce parenting stress. This paper not only suggests that a greater emphasis on parents' feeding perceptions is needed by Birth-to-Three programs, but also provides a description of parents' feeding perceptions that therapists need to consider when working with parents of young children with developmental and feeding problems.

Descriptions of parents' feeding perceptions

A unique aspect of this study was its attention to parents' perceptions of the positive aspects of feeding their child. As mentioned in the literature review, little information was found in the literature regarding parents' perceptions of rewarding experiences in feeding their young children with developmental and feeding problems. Early intervention professionals tend to focus on the problematic aspects of feeding a child with developmental and eating problems, rather than understanding the positive perceptions

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these feeding interactions can have on family members (Zeitlin & Williamson, 1994). As a result of the lack of research information, most of the positive feeding behaviors mentioned in the scale questions of the Feeding Questionnaire did not match the rewarding feeding behaviors described by parents in response to the open questions. However, a significant negative correlation was found between the frequency of the positive scale item "child sits long enough to complete the meal", and parenting stress on the Difficult Child subdomain ($p = .0001$).

The strength of this correlation suggests that professionals should consider asking parents of young children with developmental and eating problems if their child sitting long enough to complete meals is a rewarding feeding behavior that they feel needs to be addressed with their child. Understanding parent's perceptions of positive feeding behaviors may be relevant for helping them to reduce their levels of parenting stress. It appears that the area of rewarding feeding behaviors is of crucial importance and needs to be researched further.

Consistent with an exchange theory perspective, in addition to assessing parents' rewarding feeding experiences, consideration was given to parents' perceptions of the costs of feeding. The most frequently mentioned feeding difficulties and frustrations described by parents in this study were related to their child's resisting/refusing food and concerns that their child was not getting adequate nutrition. These concerns were described most frequently in response to both the open-ended and scale scored questions related to feeding problems. The great concern described by parents in this study regarding their child resisting food and not getting adequate nutrition is completely consistent with the literature (Clark et al., 1998; Reilly & Skuse, 1992).

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Included in the literature are findings that the greatest feeding problem and frustration described by parents who have toddlers and preschoolers with developmental and eating problems is that their young child is resisting/refusing food, and not getting adequate nutrition (Pridham et al., 1989; Secrist-Mertz et al., 1997). The most frequent feeding problems reported in this study are similar to those previously mentioned for the Birth-to-Three population with developmental disabilities (Clark et al., 1998).

The literature suggests that the problems of resisting food and not eating enough are related to the early negative feeding experiences of children with developmental and eating problems (e.g. choking, reflux, and/or tube feeding) that interfere with the development of a positive association between hunger and food (Douglas & Byron, 1996; Glass & Lucas, 1990). It has been proposed that there may be a critical or sensitive period for learning to eat during the first several months of life, and if tube feeding or physical problems interfere with eating or drinking by mouth during this period the child will resist eating (Bazyk, 1990). The literature describes a relationship between parental perceptions that their preschooler is resisting/refusing food, and negative feeding behaviors demonstrated by the child and parent (Blissett, Harris, & Cunningham, 1999; Satter, 1990).

As might be expected from the relationship between food refusal and behavioral feeding problems described in the literature, the third most commonly mentioned area of feeding problems described by parents in this study was their child being unhappy and/or behaving negatively (e.g., spitting out food) while eating. Conversely, the parents described their child accepting, enjoying, and/or taking new food by mouth as the most rewarding aspect of feeding. It appears that the problems of food refusal and negative feeding behaviors may be interrelated, with the young child's food refusal resulting in

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parental behaviors that contribute to the child's negative eating behaviors and food refusal problems. For example, extreme efforts by parents to get toddlers/preschooler to eat (e.g., coaxing, force feeding) appear to increase the child's resistance to eating, because feeding becomes a power struggle in which the young child tries to assert his or her developmental separation/individuation (Delaney, 1998). It is important for professionals to understand parent's experiences related to food refusal, and to support them in consistently offering varied foods but not forcing their child to eat (Satter, 1990).

The next most frequently mentioned feeding difficulty described by parents in this study was their child's oral-motor problems. These findings are consistent with the literature indicating that parents of young children who have feeding and developmental problems frequently describe their child as having oral-motor problems, including gagging (Clark et al., 1998) and difficulty chewing and/or swallowing (Dahl et al., 1996; Reilly & Skuse, 1992). The literature further indicates that in comparison to parents of typically developing children, a significantly greater number of parents with young children who have developmental and feeding problems describe their toddler/preschooler as having problems with persistent vomiting (Singer et al., 1990), coughing, and choking (Pridham et al., 1989).

Another feeding cost described by parents in this study was the time required for feeding their child. Results of this study suggested that a distinction needs to be made between considering the total time required for feeding, and the total time required for feeding by the primary feeder. Contrary to previous studies indicating a positive correlation between total daily time spent in oral feeding and parental stress e.g. $p < .10$ (Secrist-Mertz et al., 1997), no significant relationship was found in this study between the

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total time required for feeding (by all adults who fed the child) and parenting stress. This discrepancy in findings may have been due to the lower probability level, $p < .05$, used in this study and/or the specific distinction made in this study by including all feeders in considering the total time required daily for feeding.

However, a significant positive correlation was found in this study between the average number of hours spent daily on feeding by the primary feeder and parenting stress on the Parent-Child Dysfunctional Interaction subdomain of the PSI/SF. No significant relationship was found between the number of hours worked by the primary feeder and parenting stress. These findings suggest that it is important for feeding intervention to involve other family members and care providers besides the primary feeder, and for the therapist to encourage others besides the primary feeder to participate in feeding and clean up whenever possible.

Parents' described the need for feeding assistance that included specific technical skills and support services. Most of the parents reported needing both help with specific feeding strategies and social support. Four-fifth of the parents in this study stated they needed help with feeding strategies, such as oral motor techniques, positioning for feeding, and diet and nutrition advice. One-fifth of the parents described needing social support, including assistance with parent-child feeding interactions, stress management, identifying community resources, and accessing insurance. Only one-twentieth of the parents described needing no assistance. Parents' comments indicated a need for a transdisciplinary and family-centered team approach to feeding that provides specific feeding strategies and social support. While this wholistic family-centered approach to feeding is consistent with the stated mission of the Birth-to-Three programs (Connecticut

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Birth to Three Nutrition Task Force, 2000), parents spontaneously reported the need for a more wholistic family-centered approach to feeding by Birth-to-Three providers that includes specific feeding strategies and/or social support.

Consistent with the literature, parents in this study reported that their major feeding difficulties included food refusal, negative meal time behaviors related to food refusal, oral motor problems (Clark et al., 1998) and difficulty chewing and/or swallowing (Dahl et al., 1996; Reilly & Skuse, 1992). These areas of concern appear to be related to both parent-child interactions and biological characteristics of the child which are influenced by his/her diagnosis. The multifaceted nature of these problems appears to support the use of the family systems and social exchange theories in considering parents' feeding perceptions regarding their young child with developmental and eating problems.

Family Systems Theory as a theoretical foundation for understanding parents' feeding perceptions

This dissertation appears to support the use of family systems theory as a theoretical foundation for understanding parents' feeding perceptions. Mealtimes typically address many family functions simultaneously, serving as a maintenance task through the nourishment they provide, while also contributing through the interpersonal interactions they provide, to managing the family's emotional climate, identity tasks, and boundary tasks (Anderson & Sabatelli, 1995; Zeitlin & Williamson, 1994). When a child has developmental and eating problems, the amount of time needed for one or both parents to focus on feeding as a maintenance task can interfere with the family's ability to carry out their other tasks (Zeitlin & Williamson, 1994).

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Family systems theory offers a possible explanation for the fact that although only a few of the specific feeding behaviors were found to significantly correlate with parenting stress (5 out of 56), a relatively high proportion of overall feeding satisfaction measures were significantly correlated (1 out of 4 showing a significant negative correlation with parenting stress and a second approaching a significant negative correlation).

The relative lack of association between specific child feeding behaviors and parenting stress is consistent with the family systems theory emphasis on the cumulative influence of stressors and the adjustments made in the family system to respond to stress. Rather than a single feeding behavior independently resulting in high parenting stress, stressors on the family system are cumulative and would appear to put noticeable stress on the family system only after they collectively reach a critical threshold (Anderson & Sabatelli, 1995).

A second finding in this study that can be explained by family systems theory is the diverse scores found in parents' ratings of their overall satisfaction with feeding. Family systems theory proposes that while all families have to execute the same basic maintenance tasks, such as feeding young children, each family is unique in the specific policies and procedures it uses to carry out these tasks (Anderson & Sabatelli, 1995; Zeitlin & Williamson, 1994). The implication of this variation between families is that while the theoretical constructs of the family systems theory can provide a framework for understanding the feeding perceptions of parents who have young children with developmental and eating problems, the emphasis in the theory that these principles must be applied to families on an individual bases helps to explain the variation found between families in this study.

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The proposition of family systems theory that the family must be considered as interacting with other systems also helps to explain the results of this study. The three most frequently mentioned responses regarding parents' greatest feeding frustrations and needs included issues related to different but related systems. Parents' responses included problems associated with family system interactions (child's negative feeding behaviors), the subsystem of the individual toddler/preschooler's biological problems (oral-motor problems including chewing and swallowing), and the suprasystem of societal service delivery (including such things as the availability of feeding intervention services and financial assistance for tube feeding formulas). Eighty percent of parents in this study described needing help with specific feeding techniques, information, and advice, and 20% reported needing social support including counseling and assistance with accessing insurance and support services.

As described in the literature review, these findings are consistent with the research, which strongly suggests that parenting stress is affected by the impact of family dynamics such as spousal support (Anderson & Sabatelli, 1995; Beckman, 1991; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999), the subsystem of the individual child's biological factors related to their developmental and feeding problems (Humphry & Rourk, 1991; Innocenti et al., 1992; Secrist-Mertz, Brotherson, Oakland, & Litchfield, 1997; Welch, 1996), and the suprasystem societal impact of the service delivery system affecting physician behaviors (Larson, 1998).

In order to account for the multiple influences affecting parenting stress when children have developmental and eating problems, the family system should be viewed in relation to its interactions with the individual child's biological subsystem and the societal

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suprasystem affecting service delivery and parent-professional interactions (Sloman & Konstantareas, 1990).

Viewed in this way as part of the General Systems Theory (GST) from which it was derived, family systems theory emphasizes the importance of considering the multiple factors influencing families who have children with developmental and feeding problems (Whitchurch & Constantine, 1993). Sloman and Konstantareas (1990) suggest that evaluation and treatment of children with developmental problems should consider not only interactions within the family system but also include biological and cognitive perspectives on the subsystem of the child with developmental problems, and the suprasystem of cultural influences on the family. This consideration of the family system affecting and affected by other systems acknowledges that control over family system behavior does not reside in any individual family member, but proposes that the impact of a single member (such as a young child with developmental and eating problems) might have a proportionally high degree of impact on the family system (Whitchurch & Constantine, 1993).

Social Exchange and Social Comparison Theories as a foundation for understanding parents' feeding perceptions

In addition to family systems theory, the Feeding Questionnaire follows the principles of Social Exchange theory in its consideration of the various factors effecting parents' perceptions of their feeding rewards, costs, and overall satisfaction with feeding. This focus on parents' perceptions rather than feeding observations is consistent with the Exchange Theory concept that individuals determine their overall satisfaction with interpersonal relationships by assessing how their experiences compare to their

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expectations (Waldron-Hennessey & Sabatelli, 1997). Along with exchange theory, the concepts of social comparison theory also help to explain the results of this study.

One finding from this study that can be explained through an exchange and social comparison theory perspective is that parents' perceptions of overall feeding satisfaction differed from the assessment of feeding difficulties as reported in the medical literature. Parents of children with PDD/Autism reported significantly lower ratings of overall satisfaction with their feeding experience than parents of children with Cerebral Palsy. This description by parents of children with PDD/Autism of overall satisfaction with their feeding experience appears to conflict with the medical literature which indicates that children with Cerebral Palsy often have complex eating problems that significantly interfere with feeding, while children with PDD/Autism have only mild feeding problems such as picky eating (Burklow, Phelps, Schultz, McConnell, & Rudolph, 1998; Connecticut Birth to Three Nutrition Task Force, 2000; Quinn, 1995; Reilly & Skuse, 1992).

This problem of differing perceptions between parents and professionals was illustrated by one mother in this study who reported that she had fired her child's pediatrician because he told her that children with Autism do not have feeding problems. She stated that because she knew of four other autistic children besides her son who had feeding problems, including refusing to eat and throwing food, it was clear this physician didn't know what he was doing. It appears that while the views of both the mother and pediatrician were consistent with the literature, their perceptions and definitions of problematic feeding differed.

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A common assumption among professionals is the belief that the severity of a child's physical pathology is positively related to the degree of family stress. However, in reality research indicates that milder forms of child dysfunction often distress families most. The concept of the comparison level suggests that it is primarily parents' perceptions of problems that affect their unhappiness and need for assistance (Sloman & Konstantareas, 1990). The more normal appearance and lack of nutritional deficiencies of children with PDD/Autism and feeding problems may lead parents and/or professionals to assume that the child's feeding problems are caused by the child's laziness or dislike of the parent. These assumptions, in turn, may increase parents' dissatisfaction with the feeding experience (Sloman & Konstantareas, 1990).

The concept of the Comparison Level, which is central to Social Exchange theory, can help to explain this discrepancy. Social exchange theory describes an individual's satisfaction with an aspect of his or her life as being guided by the Comparison Level (CL), the standard people use to assess a situation or relationship's costs and rewards. The CL is set in terms of ones' expectations of what is realistically obtainable as determined through societal norms and past experiences (Waldron-Hennessey & Sabatelli, 1997).

This relationship between parents' expectations and experiences appeared to emerge as a central theme influencing parents' descriptions of their feeding perceptions. Several parents expressed that while feeding their child was difficult, the struggle with feeding was something they accepted given their child's developmental problems. However, other parents expressed concerns that their child was not progressing in feeding in an age

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appropriate way. It may be that effective coping by parents who have children with developmental and feeding problems involves a process of lowering their CL expectations from the normative standard used for typically developing children to expectations that are consistent with having a child with developmental and eating problems. This may be easier to do if the child is acknowledged by professionals and society in general as being different from the norm, such as children with Cerebral Palsy, than when children look more "normal", such as children with PDD/Autism.

Social exchange theory offers an explanation for this focus by parents' on the relationship between feeding expectations and experiences, describing overall feeding satisfaction as resulting from the relationship between perceived feeding costs and rewards. Perceived feeding costs and rewards are judged based on the degree to which an individual's experiences matches his or her expectations. Based on Social Exchange theory measures of overall satisfaction on the Feeding Questionnaire would therefore be expected to be high if parents' perceived feeding experiences exceeded their expectations, and low if their perceived experiences fell below expectations (Sabatelli & Shehan, 1993; Waldron-Hennessey & Sabatelli, 1997).

Exchange theory proposes that people set their comparison level standard of expectations based on their individual perceptions of societal norms (Sabatelli & Shehan, 1993; Waldron-Hennessey & Sabatelli, 1997). Consistent with this exchange theory explanation, parents' descriptions of their most rewarding feeding experiences were consistent with the expectations held in our society for the feeding behaviors expected by toddlers and preschoolers. Nearly half the parents reported that they felt rewarded when

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their child accepts, enjoys, and/or takes new food, which are expected behaviors for typically developing toddlers and preschoolers.

Parents' in this study also described experiences that fell below societal expectations as their greatest feeding problems. The greatest problems with feeding described by the parents were their child's persistent food refusal, related negative behaviors, and difficulties with age expected oral-motor eating skills. These problematic feeding experiences appeared to contrast greatly with the feeding expectations society holds for typical toddlers and preschoolers. Several parents also specifically referred to societal expectations when describing their greatest feeding concerns, relating their concern that their child's food refusal or inability to self-feed should have gone away by now and that they feared their child would always have these difficulties.

Given the theme that emerged from this study regarding the importance of parents' expectations in influencing their perceptions of feeding experiences, Social Comparison theory appears particularly helpful for understanding parents' feeding perceptions. The social comparison literature describes how individuals use cognitive processes to mediate their responses to stress (Croyle, 1992) and cope with stressful events (Taylor, Buunk, & Aspinwall, 1990). Parents' perceptions of their child's feeding behavior in this study appeared to be affected by how their feeding experiences related to their feeding expectations. The parents' feeding expectations appeared to be influenced by comparisons of their child's feeding behavior with the feeding behavior of other typically or atypically developing children, or with their child's own past feeding behaviors as reflected in the progress their child made in feeding.

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Social Comparison theory describes specific types of comparisons that parent's may use in dealing with stressful situations such as their perceptions of feeding a child with developmental and eating problems. Awareness of the comparison level standard held by parents can be helpful for therapists who are working with families to improve their child's feeding skills. Two major cognitive processes used in dealing with stress are described by Social Comparison theory, downward social comparisons (comparing ones self with others who are less fortunate or less capable) and upward social comparisons (comparing ones self with others who are more capable or better off). Downward and upward social comparisons may be used as attempts to cognitively mediate stress and manage ones emotions. However, upward comparisons do not necessarily lead to negative affect, and downward comparisons to positive affect (Hemphill & Lehman, 1991).

The critical factor affecting the impact of upward and downward comparisons on emotional well-being appears to be related not to which type of comparison is made but instead to the individual's perception of what the comparison means (Hemphill & Lehman, 1991). Downward social comparisons can affect an individual positively if they focus on their comparative superiority or good fortune, or negatively if they perceive it as an indication that their own situation can get worse. Likewise upward social comparisons can affect an individual positively if they focus on the possibility that they can become better off than they are currently, or negatively if they focus on their current relative inadequacy and misfortune relative to others (Taylor, Buunk, & Aspinwall, 1990).

Coping and the impact of feeding intervention services

In addition to their perceptions of feeding costs and rewards, parents were asked to describe their perceptions of the Birth-to-Three feeding intervention provided for their

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family. Slightly less than half the parents described feeding intervention in terms of its having a positive impact with no mention of a negative impact. Parents reported two ways that therapists had a positive impact on feeding.

Some parents described interaction strategies developed jointly by the therapist and parent that resulted in less food refusal and negative behaviors by their child. Other parents reported that although there was no improvement in their child's food refusal and negative feeding behaviors, they were supported by the therapist's participation in the most difficult aspects of feeding. By watching the therapist experience their child's problematic eating behaviors, such as spitting food and screaming, parents felt they were helped to realize that their child's eating problems were not their fault.

Social comparison theory would explain the parents' perceptions of feeding intervention as having a positive impact if it improved their child's feeding behaviors because their child's improved feeding behavior compared more favorably to other children and/or their own child's past feeding behaviors. The therapist's participation and difficulties in feeding would be explained as beneficial because it showed parents' that their feeding ability compared favorably with the feeding abilities of a professional feeding expert.

While slightly less than half the parents described feeding intervention as having a positive impact only, approximately one quarter described intervention as having both positive and negative impacts, and one quarter described intervention as having no impact or a negative impact only (11.5% describing each of these categories). Parents' comments regarding the negative impacts of feeding intervention related to the intervention not

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addressing parents' goals, not fitting into family routines, or causing the family to feel inadequate for not doing enough to help improve their child's feeding.

For example, one parent conveyed that her child's therapist provided a positive impact by teaching her how to introduce cup drinking to her child, but a negative impact because she told the mother she was not spending enough time working on cup drinking. The mother reported that having a new baby had made her too tired to work as long as she should on cup drinking with her disabled child, and she would cry every night because she knew she was letting her son down. The literature describes such conflicts between parents and professionals regarding the level of involvement parents should have, and stresses the importance of therapists respecting parent's abilities and preferences regarding the amount of involvement they have in carrying out their child's therapy program (Bazyk, 1989).

Parents who described feeding intervention as having a positive impact only or both positive and negative impacts had significantly lower levels of parenting stress than parents who described feeding treatment as having no impact or a negative impact only. While the lack of reliability and validity of the Feeding Questionnaire require caution in considering this relationship between perceived positive outcomes from feeding treatment and lower parenting stress, it is especially interesting given the established relationship in the research between decreased parenting stress and positive child developmental outcomes (Cowen, 1998; Deater-Deckard, 1996). The relationship between a perceived positive impact from feeding intervention and decreased parenting stress may suggest that feeding intervention which is perceived by parents as having a more positive impact is more effective in reducing parenting stress.

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Another finding related to feeding intervention that underscores the need for Birth-to-Three service providers to gain a greater understanding of parents' feeding perceptions was the frequent lack of agreement between parents' descriptions of their feeding goals and the feeding goals listed in their child's Birth-to-Three record. Feeding goals in the Birth-to-Three record are supposed to reflect the goals that are most important to the parents (Connecticut Birth to Three Nutrition Task Force, 2000). Yet when 30 feeding goals described by parents from the Feeding Questionnaire were compared with the combined feeding goals in their child's Birth-to-Three record, only one third matched completely. Approximately half of the goals described by the parents partially matched the goals in their child's record, and one sixth did not match at all. These results suggest that either the child's therapist did not clearly understand the parents' goals when developing the feeding goals in the child's Birth-to-Three record, or the parents' goals had changed but the goals in their child's record had not been revised.

Implications of this study for family-centered feeding intervention

An initial implication of this study for clinical practice is that Birth-to-Three programs need to focus more on the feeding perceptions of parents who have young children with developmental and eating problems. The findings of this study that developmental and feeding problems are problematic for parents, that half the parents experience clinically significant levels of parenting stress, and that many parents describe feeding as their least favorite child care task, support the need for early intervention providers to evaluate and, if necessary, address parents' feeding perceptions. The literature supports the findings of this study suggesting that it is beneficial for early intervention providers to evaluate parents' perceptions of feeding and feeding intervention (Zeitlin & Williamson, 1994).

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Following assessment of parents' feeding perceptions, feeding intervention services should be provided to parents of young children with developmental and eating problems who want and feel they need feeding intervention (Affleck, Tennen, & Rowe, 1991).

Feeding interventions for young children with developmental and eating problems are most affective when professionals understand the unique sources of stress experienced by each family (Handleman, 1995), and use this understanding to provide feeding intervention that assists the family in coping effectively with these stresses (Humphry, 1989). An understanding of parents' perceptions of their young child's feeding behaviors provides a foundation for affective family-centered feeding intervention by clarifying parents' feeding concerns, pleasures, satisfaction, and goals (Bernheimer & Keogh, 1995; Crowley, 1995; Deal et al., 1994).

This need for professionals to understand and address parents' feeding perceptions was illustrated by the significantly lower ratings of overall feeding satisfaction by parents of children with PDD/Autism compared to parents of children with Cerebral Palsy. This is in contrast to the belief of professionals that Cerebral Palsy causes more problematic feeding experiences for parents. Because there may be differences between the perceptions of feeding problems by parents and professionals, it is important that feeding evaluations include measures of parent perceptions as well as the observations of professionals.

A second issue that should be addressed by clinicians is the high degree of food resistance and negative feeding behaviors described by parents in this study and confirmed by the literature regarding parents of young children who have developmental and eating problems. Therapists need to provide parents with information and modeling that assists them in understanding that their child's resistance to eating and associated negative

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feeding behaviors are based on the child's physical problems and/or medical history and are not a negative expression by the child towards the parent.

In addition to understanding the problematic aspects of feeding, as is most commonly done in feeding assessments, the significant negative relationship found between parenting stress and the positive behavior of sitting long enough to complete the meal suggests that therapists should also consider parents' positive feeding perceptions. Therapists can then try to promote the feeding behaviors parents find most rewarding, and point them out to parents during feeding.

Evaluations of parents' perceptions of feeding should carefully monitor both parents' overall feeding satisfaction and parenting stress. The results of this study indicate that it is important for early intervention providers to periodically assess and be sensitive to parents' overall satisfaction with feeding, as well as to monitor parenting stress. By staying aware of the parents' current overall feeding perceptions and levels of parenting stress, therapists will have helpful information regarding when it is most appropriate to discuss introducing additional feeding demands on the parents, child, and family such as introducing foods of greater consistency.

An awareness of parents' levels of stress may also help therapists to better recognize and address parents' needs for counseling services. During the interviews a number of parents spontaneously expressed that with all of their difficulties related to having a child with developmental and eating problems professional counseling support is needed. The parents also suggested that these counseling services should be actively offered to parents by therapists working in the Birth-to-Three programs.

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An implication of parents' reports regarding the negative impacts of feeding intervention is that therapists should make every effort possible to integrate feeding interventions into the family routine, address the parents' feeding concerns, and not imply that parents are not doing enough to improve their child's feeding abilities. Hanft (1988) states that identifying families needs, resources, and desired degree of involvement in early intervention services is the foundation for appropriate collaboration between parents and professionals in the Birth-to-Three programs. One theme that emerged from this study was that parents should be approached as colleagues with professionals in the feeding intervention process.

Given the need expressed in the literature for developing family-centered evaluation and intervention services that are grounded in a theoretical understanding of parenting and the family (Humphry, 1989; Innocenti, Hollinger, Escobar, & White, 1993), the family systems, social exchange, and social comparison theories appear promising for guiding feeding evaluation and intervention services. These three theories were helpful in explaining many aspects of parents' feeding perceptions found in this study, including the multiple perspectives of family dynamics, biological factors related to the child with developmental and eating problems, and societal factors affecting the service delivery system. Greater efforts are needed to educate early intervention professionals on these and other current theories regarding feeding, nutrition, parenting, family studies, and cultural diversity (Connecticut Birth to Three Nutrition Task Force, 2000). These areas of study should also be more extensively covered in the pre-professional, professional, and graduate education levels in the allied health and medical fields (Humphry, 1989).

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The family systems, social exchange, and social comparison theories provide a framework for considering the feeding perceptions of parents who have young children with developmental and eating problems. Family systems theory directs therapists to consider parents' perceptions of their child's feeding within the context of the family system and the sub and suprasystems influencing the family system. Subsystem influences would include the child's biological factors related to his or her developmental and eating problems, while suprasystem influences would relate to such influences as the service delivery system. The social exchange and social comparison theories encourage therapists to consider parents' feeding expectations and experiences, and how the relationship between parents' feeding expectations and experiences affect their overall feeding satisfaction and levels of parenting stress. Finally, while the family systems, social exchange, and social comparison theories offer principles for understanding and addressing parents' feeding perceptions, these theories maintain that the principles need to be applied individually because each parent and family is unique.

As suggested by the high standard deviation of parents' overall feeding satisfaction ratings, professionals need to consider the perceptions and coping responses of parents with young children who have developmental and eating problems individually, rather than over-generalizing based on the principles of family theories (Affleck et al., 1991). The implication of the variation between parents' overall feeding perceptions is that the theoretical constructs of the family systems, social exchange, and social comparison theories must be applied individually to each parent and family to be effective.

In this study parents who were most dissatisfied with their overall feeding experience had the highest levels of parenting stress. Interpretation of this finding based on social

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exchange and social comparison theory suggests that therapists need to help parents to be realistic concerning their expectations of their child's developmental and eating skills. It could be assumed that by helping parents to match their expectations with their child's abilities, therapists can reduce parenting stress and improve overall feeding satisfaction. However, caution must be used if giving parents a "realistic" negative appraisal of their young child because parents may perceive such appraisals as an underestimation of their child's abilities by professionals (Larson, 1998). In addition, not enough is currently known about the effects of social comparisons on parental coping to justify active manipulation of parents' comparisons by professionals (Affleck et al., 1991). Given the current state of knowledge, it appears most appropriate for professionals to provide information about the child's developmental and feeding problems based on an accurate appraisal of current research, while actively listening to and not challenging parents' expressed perceptions of their feeding experiences.

Professionals should not discourage parents from comparing a problem of their infant with other infants who are doing better and worse, as such discouragement may be problematic for parents (Affleck et al., 1991). Parents' in this study, consistent with the literature, described their need for clear, accurate information regarding their child's developmental and feeding problems and the opportunity to openly express their emotions regarding their child's problem.

Therapists should provide accurate information to parents regarding their child's developmental and eating problems, then listen to and not discount parents' negative perceptions of their child. By providing clear accurate information and listening to parents, therapists can help parents develop an accurate and realistic understanding of

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their child's needs and abilities and develop a long term acceptance of their child's unique strengths and disabilities (Britner et al., 2000; Zeitlin & Williamson, 1994). A collaborative team effort between parents and professionals is needed to achieve optimal feeding skills for young children with developmental and eating problems.

Methodological Issues

The goal of this study was to gain an understanding of parents' perceptions of feeding that could be used to guide feeding intervention in the Birth-to-Three programs. Consistent with this goal, the sample included parents of toddlers and preschoolers who were current or former participants in the Birth-to-Three programs. This included children with a variety of disabilities. It was recognized that by not limiting the population in terms of diagnoses, it was likely that considerable variance would be introduced by the inclusion of families whose children had varied developmental and feeding difficulties. However, the advantage of this diversity in diagnoses and feeding problems was that it provided the opportunity to determine the common feeding perceptions and treatment implications that applied to the range of families receiving feeding intervention in the Birth-to-Three programs.

Consistent with this variation in the sample, three of the four measures of overall feeding satisfaction (e.g., the experience of feeding their child, the support received with feeding, and their balance between feeding and other aspects of their life) indicated that there was wide variability in parents' scores. The large standard deviations in the responses to these scale questions reflect the individual differences between parent's overall perceptions of feeding.

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Methodologically, this research had both strengths and weaknesses. The inclusion of rewarding feeding behaviors appeared to be a relatively unique and important factor for understanding parents' feeding perceptions. However, primarily due to the lack of available research for developing positive feeding items, most of the rewarding feeding behaviors described by the parents in the open-ended questions were not included as scale scored items in the Feeding Questionnaire. The most frequently mentioned rewarding feeding behaviors from the open-ended questions should be considered for inclusion in future scale scored items that address rewarding feeding behaviors.

It should also be noted that while the Feeding Questionnaire utilized social exchange theory by including questions about both feeding rewards and costs, the questions did not specifically ask parents to compare their feeding perceptions to what they expected. Also, while social exchange theory has been used to describe the parenting relationship, it has not previously been used to specifically consider overall feeding satisfaction, and this narrower focus to one aspect of parenting may be too limited for application of social exchange theory. It was felt that given the salience of feeding for parents of young children with developmental and feeding problems, such a use of social exchange theory was consistent with the foundations of this theory.

All of the findings regarding correlations between parental perceptions of feeding and feeding intervention as described by the Feeding Questionnaire must be interpreted with caution because the Feeding Questionnaire was designed to collective descriptive information, not as a psychometric measure of parents' perceptions of feeding or feeding intervention. Thus reliability and validity were not assessed. The items from the feeding scale were based on a variety of feeding measures and the author's clinical experience as

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an occupational therapist working with young children who had developmental and feeding problems and their families. Parents' scores on the problem frequency items had a coefficient alpha of .61, and scores on the problem intensity 1 items (frequency X frustration).63, both in the moderate to high range of score reliability within subsection items (Gall et al., 1996; SPSS Inc., 1999). The problem frustration and positive feeding behavior frequency items each had a coefficient alpha of .47, in the moderate range (Gall, Borg, & Gall, 1996; SPSS Inc., 1999). While the coefficient alpha reflected subsections of the Feeding Questionnaire, it suggests items may have potential for development into a reliable test.

However, while further studies may build on items in the Feeding Questionnaire to develop a reliable and valid measure of parents' feeding perceptions, this was not the goal of the current study. The focus of this study was the potential usefulness of the Feeding Questionnaire as a clinical tool to guide parent-centered feeding intervention. Application of information regarding parents' perception of feeding and feeding intervention appears to be where the greatest potential for the Feeding Questionnaire lies.

An important addition to increase the effectiveness of the Feeding Questionnaire as a clinical tool to guide feeding intervention with parents of children who have developmental and feeding problems would be to include two additional open-ended questions at the beginning of the Feeding Questionnaire interview. These questions, described by Britner et al. (2000) in their study of parents with young children who had Cerebral Palsy, are 1) Tell me about who is in your family and 2) Tell me about your daily routine (Britner et al., 2000). Following these initial questions, specific questions from the feeding questionnaire which were not addressed could be related to the initial questions

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and asked in an informal way. Two parents suggested open-ended questions of this type would have been helpful during this research, commenting that it was awkward to respond to formal questions at the beginning of the interview. They also commented that the ratings of feeding frustration preceding a complete open-ended description of feeding felt awkward.

This study had a number of limitations in terms of its generalizeability. Since it involved only 31 subjects, and participants were a self-selected rather than a random sample, the results may not be typical of families of toddlers and preschoolers with developmental and feeding problems. It must also be noted that most of the families were participants in the Connecticut Birth-to-Three program. Their experiences may differ from parents in Birth-to-Three programs in other states. The decision to exclude parents who could not speak English also may have limited the generalizeability of this study, since non-English speaking parents are part of the Birth-to-Three population.

A methodological limitation of this study is that scale score questions regarding specific oral-motor and food refusal problems preceded all but one of the open-ended questions regarding feeding problems, and may have prompted parents to describe feeding problems mentioned in the scale questions during the open-ended questions. A second methodological concern is that questions regarding perceptions of Birth-to-Three feeding intervention were proposed to a sample including families who were both current and former participants in the Birth-to-Three program. The differing perspectives of reporting present and past feeding perceptions may have led to significantly different perceptions being included in this study from these two groups.

Implications for future research

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It seems imperative to conduct further theoretically grounded research to determine the best ways to involve parents in feeding intervention so they will perceive feeding intervention as having a positive impact (Innocenti et al., 1993). This study suggests the need for further research regarding parent's perceptions of feeding and feeding intervention using a large, random sample of parents who have young children with developmental and feeding problems. Greater research especially is needed regarding the rewarding aspects of feeding for parents of toddlers and preschoolers with developmental and eating problems. Parent's descriptions of rewarding feeding experiences from this study may provide a first step in developing scale score questions regarding positive feeding perceptions for future studies. Scale score questions regarding feeding rewards may then be used to develop an assessment of the relationship between feeding costs, rewards, and overall feeding perceptions that evaluates the applicability of the social exchange theory for considering parent's feeding perceptions.

Further research also is needed to assess the effects of different types of family-centered feeding interventions on parents' perceptions of feeding and parenting stress. This type of research is needed to test theoretically based approaches for how to involve parents most effectively in feeding intervention. If the goal of family-centered feeding intervention is to involve and support parents most effectively, then measures of parents' feeding perceptions and overall parenting stress should be included in feeding treatment outcome measures.

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APPENDIX

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Appendix A: Research Involving the Parenting Stress Index and Parenting Stress Index/Short Form

The Parenting Stress Index (PSI) is a reliable and valid self-report measure commonly used in research and clinical practice. The PSI measures an individual's stress related to their role as a parent. The items of the PSI were developed from the literature on infant development, parent-child interaction, child attachment, child abuse and neglect, child psychopathology, child management, and stress. An expert panel used the literature to develop a pool of items. Each of the items was then rated for relevance by a panel of six parent-child relation professionals. The most relevant items were field tested to derive the 101 items of the PSI (Abidin, 1995a).

The Parenting Stress Index/Short Form (PSI/SF) was developed based on the full length PSI, incorporating the full original wording of specific items from the full length PSI. "The PSI/SF was developed through a series of replicated factor analyses, which ... resulted in a three factor solution as the best description of the data" (Abidin, 1995a, p.57). While the PSI/SF is newer and has not been as extensively validated as the PSI, its shorter length taking 10 rather than 20 minutes to complete may result in increased attention to test questions by parents (Abidin, 1995a).

Several studies of parenting stress using the Parenting Stress Index (PSI) have indicated that parents of toddlers and preschoolers with extremely low birth weight, developmental delays, and developmental disabilities have significantly higher levels of parenting stress (Beckman, 1991; Singer, Salvatore, Guo, Collin, Lilien, & Baley, 1999). Beckman (1991) found that parents of toddlers and preschoolers with disabilities had

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significantly greater stress on the parent domain, child domain, and total stress score of the PSI. However, most studies involving parents of toddlers and preschoolers with developmental problems reported significantly increased stress on the PSI in the parent domain but not the child domain, indicating the increased stress was related to the child's characteristics (Abidin, 1995a; Innocenti, Huh, & Boyce, 1992; Singer et al., 1999). Parents of children with failure-to-thrive problems whose children had greater developmental delay reported significantly greater stress in the Child Domain but not the Parent Domain of the PSI (Singer, Song, Hill, & Jaffe, 1989).

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Appendix B: Demographic Questionnaire

Subject # ____
Date:_____

Introduction First, I'd like to get some background information about you and your family.

1. Child Demographic Questions

a. Medications/verify/Changes:_____

b. Food allergy No___ Yes___

c. Verify medical status:_____

d. Seizures: No____ Yes_____ If yes, within past 6 months No____ Yes____

e. Length of NICU stay None_____ Yes_____ Initial length_____

f. Hospitalizations/emergencies in past 6 months No____ Yes_____ Number _____

g. Onset of feeding problems-(constipation, diarrhea, colic, vomiting, food refusal, taking food off spoon difficulties, swallowing difficulties)

Date:_____

Type:_____

h. Current weight reported:_____

i. Current height reported:_____

j. Tube as well as oral fed: No____ Yes_____

Bolus or Continuous & Amount:_____

k. Had a fundoplication: No____ Yes____

l. significant neonatal or perinatal deviation/disease: No___ (Skip to) Yes___

Describe:_____

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m. prematurity: No___ Yes____ Born at what gestational age_____

n. Low birth weight No___ Yes____

o. Birth weight_____

p. Length of NICU stay None_____ Yes_____ Initial length_____

q. Experience of difficulty/complications during pregnancy: No___ (If no skip next)

Yes___ Specify_____

r. Length of mother's hospitalization during infant's birth_____

s. Subsequent hospitalizations/emergencies No____ Yes_____

t. Number emergencies/hospitalizations since NICU___

u. Describe feeding problems:

_____

_____

_____

_____

_____

_____

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2. Family factors Subject #:____ Date:_____

a. Household Members	**Relationship to child**	**Age**
Mom		
Dad		
Child		
Child		
Child		

b. Child care arrangements for target child: Parent Day Care Center/amt._____

Relative/amt: _____

c. Parents Occupations: Occupation Hours

Mother:_____

Father:_____

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3. Feeding Questions Subject #:____ Date:_____

a. Primary feeder: Mother____ Father____ Other_____

Primary feeder percentage of feeding: _____

b. Percentage feeding spouse does:____

c. Percentage feeding others do: ____Describe: _____

d. Primary feeder history feeding problems No__ Yes___

Describe:_____

e. Parent health problems No__ Yes___

Describe who/what:_____

f. Sibling disabilities or chronic health problems: ___ No ___ Yes

Who/what: _____

g. Onset and types of feeding problems-define as constipation, diarrhea, colic, vomiting, food refusal, taking food off spoon difficulties, swallowing difficulties:_____

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Appendix C: Information about Yourself

Subject #_____
Date _____

Age: _____

Race: Non-Hispanic White _____ Black _____ Hispanic _____
Native American_____ Asian/ Pacific Islander _____
Other: Specify_____

Marital Status: Married _____ (Number of years _____) Divorced_____
Single _____ Separated _____ Widowed _____

Education: Less than 12th grade _____ High School_____
Vocational/ Some college _____ College Graduate _____
Graduate Degree _____

Occupation: _____

Employment Status: Part Time _____ (number of hours per week) _____
Full Time _____ (number of hours per week) _____

Annual Household Income: Less than $15,000 _____ $15,000-25,000 _____
$26,000-$50,000 _____ $51,000-100,000 _____
$101,000-200,000 _____ Over 200,000 _____
Is this a 1 or 2 income family: 1 _____ 2_____

How satisfied are you with your balance between career, personal interests and parenting?
Very Unsatisfied 1 2 3 4 5 Very Satisfied

Overall, how satisfied are you with the amount of support you have with parenting?
Very Unsatisfied 1 2 3 4 5 Very Satisfied

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Appendix D: Feeding Questionnaire-Parent copy

Section A. In this section I am going to ask you about your overall experiences and desires in feeding your child.

1. What are your greatest concerns regarding feeding your child (up to 5 things)?
2. When considering the various aspects of caring for your child that you like from most to least enjoyable, where does feeding rank?
3. How many hours a day does it take on average, to feed your child?
4. What is your child's average amount of food eaten daily?

Section B. Now I'm going to describe several feeding behaviors that parents sometimes describe as problematic. **For each behavior, let me know whether your child has this problem, and if so how often. Rate the problem 0 If your child never has the difficulty; 1 Has difficulty up to 25% of the time; 2 Up to 50% of the time; 3 Up to 75% of the time 4 More than 75% of the time.** For each problem that occurs, I will also ask you to rate your degree of frustration using a 0 to 4 scale:

---

0 Not frustrating 1 2 3 4 Extremely frustrating

Here is a copy of the rating scale as a reminder.

Do you have a problem with your child:

1. Lacking adequate postural control required for eating well
2. Lacking adequate movement skills required for eating well
3. Choking/coughing on food
4. Eating too slowly
5. Taking too long to feed
6. Refusing or resisting eating enough food to maintain adequate nutrition
7. Refusing or resisting drinking enough liquids to maintain adequate hydration
8. Refusing or resisting food unless distracted (by T.V., toys, etc.)
9. Refusing or resisting age appropriate textures of food

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10. Spitting out food
11. Eating too quickly
12. Eating too much, exceeding his nutritional requirements and risking obesity
13. Stuffing the mouth with food
14. Eating nonfood items
15. Crying or screaming during meals
16. Signs of getting food in lungs (e.g. wheezing)

Section C. In this section, I'm going to describe feeding behaviors which many parents describe as desirable, but sometimes lacking. **Let me know if this behavior occurs, and if so how frequently. Rate the positive behavior 0 if it never occurs; 1 Rarely-up to 25% of the time; 2 Sometimes-up to 50% of the time; 3 Often-up to 75% of the time 4 Very often-more than 75% of the time.**

Do you have the positive experience of your child:

1. Accepting touch on the face so the feeder can wipe the mouth
2. Accepting touch of the food and/or spoon during feeding
3. Chewing in an age appropriate way
4. Opening mouth as the spoon approaches
5. Taking food off the spoon with the lips
6. Keeping food in the mouth while eating
7. Drinking in an age appropriate way
8. Sitting long enough to complete the meal

Section D.

1. What do you find most frustrating in feeding your child?

2. What aspects of feeding your child do you find most rewarding?

3a. What if any areas of feeding your child do you need help with?

3b. Please explain.

4a. Is feeding treatment part of your child's early intervention program?

4b. If so, what does it involve and what impact does it have?

5a. What are your goals for your child's future feeding abilities?

5b. Please explain.

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6. Overall, how satisfied are you with the amount of support you receive with feeding from family and friends?

Very Unsatisfied 1 2 3 4 5 Very Satisfied

7. Regarding support with feeding, do you let other people feed your child and if so, how comfortable do you feel doing this?

8a. How satisfied are you with your balance between feeding your child, other family responsibilities, personal interest and work responsibilities:

Very Unsatisfied 1 2 3 4 5 Very Satisfied

8b. Please explain.

9a. Overall, how satisfied are you with the experience of feeding your child?

Very Unsatisfied 1 2 3 4 5 Very Satisfied

9b. Please explain.

10. Are there any other issues which affect your feeding frustration/rewards?

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Appendix E: Feeding Questionnaire-Interviewer Form

Subject #_____
Form # ____
John's client: Yes____ No____
Agency: RA____ Other: _____
Date_____
Taped: Yes___ No___

Section A. In this section I am going to ask you about your overall experiences and desires in feeding your child.

1. What are your greatest concerns regarding feeding your child (up to 5 things)?
Amt. Food for growth; Amt. food for functioning; describe "eat normally"; family impact

2. When considering the various aspects of caring for your child that you like from most to least enjoyable, where does feeding rank?
What makes (un)enjoyable); which times during feeding; aspects of feeding

3. How many hours a day does it take on average, to feed your child?
Avg. daily total
4. What is your child's average amount of food eaten daily?
Average daily: Liquid by mouth, specific size solid by mouth, liquid by tube, confirm

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Section B. Now I'm going to describe several feeding behaviors that parents sometimes describe as problematic. **For each behavior, let me know whether your child has this problem, and if so how often. Rate the problem 0 If your child never has the difficulty; 1 Has difficulty up to 25% of the time; 2 Up to 50% of the time; 3 Up to 75% of the time 4 More than 75% of the time.**

For each problem that occurs, I will also ask you to rate your degree of frustration using a 0 to 4 scale:

---

0 Not frustrating 1 2 3 4 Extremely frustrating

Here is a copy of the rating scale as a reminder.

If never occurs, frustration 0 automatically; rate frustration level while occuring

Do you have a problem with your child:

1. Lacking adequate postural control required for eating well 0 1 2 3 4 **0 1 2 3 4**
2. Lacking adequate movement skills required for eating well **Head/mouth** 0 1 2 3 4 **0 1 2 3 4**
3. Choking/coughing on food 0 1 2 3 4 **0 1 2 3 4**
4. Eating too slowly 0 1 2 3 4 **0 1 2 3 4**
5. Taking too long to feed **eat & drink included** 0 1 2 3 4 **0 1 2 3 4**
6. Refusing or resisting eating enough food to maintain adequate nutrition0 1 2 3 4 **0 1 2 3 4**
7. Refusing or resisting drinking enough liquids to maintain adequate hydration0 1 2 3 4 **0 1 2 3 4**
8. Refusing or resisting food unless distracted (by T.V., toys, etc.) 0 1 2 3 4 **0 1 2 3 4**
9. Refusing or resisting age appropriate textures of food 0 1 2 3 4 **0 1 2 3 4**

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10. Spitting out food **Actively** 0 1 2 3 4 **0 1 2 3 4**

11. Eating too quickly 0 1 2 3 4 **0 1 2 3 4**

12. Eating too much, exceeding his nutritional requirements and risking obesity 0 1 2 3 4 **0 1 2 3 4**

13. Stuffing the mouth with food 0 1 2 3 4 **0 1 2 3 4**

14. Eating nonfood items 0 1 2 3 4 **0 1 2 3 4**

15. Crying or screaming during meals 0 1 2 3 4 **0 1 2 3 4**

16. Signs of getting food in lungs (e.g. wheezing) 0 1 2 3 4 **0 1 2 3 4**

Section C. In this section, I'm going to describe feeding behaviors which many parents describe as desirable, but sometimes lacking. **Let me know if this behavior occurs, and if so how frequently. Rate the positive behavior 0 if it never occurs; 1 Rarely-up to 25% of the time; 2 Sometimes-up to 50% of the time; 3 Often-up to 75% of the time 4 Very often-more than 75% of the time.**

Do you have the positive experience of your child:

1. Accepting touch on the face so the feeder can wipe the mouth 0 1 2 3 4

2. Accepting touch of the food and/or spoon during feeding 0 1 2 3 4

3. Chewing in an age appropriate way 0 1 2 3 4

4. Opening mouth as the spoon approaches 0 1 2 3 4

5. Taking food off the spoon with the lips 0 1 2 3 4

6. Keeping food in the mouth while eating 0 1 2 3 4

7. Drinking in an age appropriate way 0 1 2 3 4

8. Sitting long enough to complete the meal **willingness** 0 1 2 3 4

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Section D.

1. What do you find most frustrating in feeding your child?
Specific things child does and doesn't do that most frustrate feeder

2. What aspects of feeding your child do you find most rewarding?
New categories; specific things child does that reward feeder, describe "improvement"

3a. What if any areas of feeding your child do you need help with?
Help addressing what specific aspects, how choice impacts feeding frustration /rewards

3b. Please explain.

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4a. Is feeding treatment part of your child's early intervention program? No__ Yes___

4b. If so, what does it involve and what impact does it have?
Specific areas addressed, how it has(n't) helped with frustration/rewards

5a. What are your goals for your child's future feeding abilities?

5b. Please explain.
Why are these your goals, how accomplishing will affect feeder frustration/rewards

6. Overall, how satisfied are you with the amount of support you have with feeding?

Very Unsatisfied 1 2 3 4 5 Very Satisfied

Why? How does being (un)supported affect frustration/rewards

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7. Regarding support with feeding, do you let other people feed your child and if so, how comfortable do you feel doing this?

8a. How satisfied are you with your balance between feeding your child, other family responsibilities, personal interest and work responsibilities:

Very Unsatisfied 1 2 3 4 5 Very Satisfied

8b. Please explain.
Why (un)satisfied

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9a. Overall, how satisfied are you with the experience of feeding your child?

Very Unsatisfied 1 2 3 4 5 Very Satisfied

9b. Please explain.
Why (un)satisfied?

10. Are there any other issues which affect your feeding frustration/rewards?

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Appendix F: Family Demographics and Medical History Form

Subject #:_____
Date:_____
Date of Parent Interview_____

I. Child Factors

a. Date of Birth_____

b. Craniofacial problems: No____ Yes___

Cleft Lip unrepaired ___ Repaired _____

Cleft Palate unrepaired ___ Repaired _____

c. Sex: M___ F____

d. Diagnoses:_____

_____

_____

_____

_____

_____

e. Disabilities (check if problem present): Legally Blind _____

Hearing Impaired _____ Seizure disorder _____ Sz in past 6 months _____

Neurologically impaired _____ Shunt _____

f. Date began Birth-to-Three services (evaluation deemed eligible): _____

g. Tube as well as oral fed: No____ Yes_____

Bolus or Continuous & Amount:_____

Nasogastric___ Gastrostomy____

h. Had a fundoplication: No____ Yes____

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i. Food allergy: No___ Yes___

Specify:_____

j. Needs supplemental oxygen: No___ Yes____

Describe:_____

k. Takes some food or liquid orally and is medically able to do both to some degree:

No__ Yes____

If no, omit from study

l. Any medical limits to oral eating: No___ Yes___

Describe_____

m. Taking medications: No___ Yes____

Specify:

_____

_____

_____

_____

_____

_____

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n. SD regarding Physical Development: GM_____ FM_____ Source:_____

Date:_____

Cognitive Development:_____ Source:_____ Date___

Personal Social:_____ Source:_____ Date_____

Self-Help/Adaptive:_____ Source:_____ Date:_____

Communication (total):_____ Receptive_____ Expressive_____

Source:_____ Date:_____

II. Infant history factors

(1) Significant neonatal or perinatal deviation/disease: No___ (Skip to 6) Yes___

Describe:_____

(2) Prematurity: No___ Yes____ Born at what gestational age_____

(3) Low birth weight No___ Yes____

(4) Birth weight_____

(5) Length of NICU stay None_____ Yes_____ Initial length_____

6. Current B-3 treatment:

6b. Date of initial IFSP_____ 6c. Date of most current IFSP _____

7. Other non-physician tx/freq: _____

7. List any goals and objectives in the child's current Birth-to-Three treatment plan that address feeding:

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Appendix G: Parent Perspectives on Feeding
Informed Consent

Dear Parents,

I am an Occupational Therapist who has worked closely with the Birth-to-Three system for many years, providing services to children with feeding problems and their families. At the present time I am completing my Ph.D. at the University of Connecticut. As part of my dissertation project, I am requesting your participation in a research study that focuses on understanding parent's perspectives on feeding issues with infants and toddlers. My research project is titled *Parent Perspectives on Feeding.* I would appreciate the opportunity to visit with you at your home or the Birth-to-Three office to discuss feeding issues and have you fill out short questionnaires. All interviews will be confidential.

The questions will take approximately an hour. If you prefer, two visits can be arranged to complete the questions. I will ask you some basic questions about your family, then focus on your experience of feeding. The feeding questions will ask you to describe what feeding is like for you, and ask you to rate certain specific aspects of feeding. Following these questions, I will ask you to fill out a short questionnaire about your overall stress related to parenting. Before visiting you to ask for your views, I will gather information from your child's Birth-to-Three records regarding his or her developmental and medical status and Birth-to-Three treatment goals. The file will not be taken out of the office. All information from your child's Birth-to-Three records and the interview will be identified by a number and kept confidential.

I realize that answering questions during a home visit will take some time and effort on your part, and I thank you in advance for considering participation. I hope that this study will provide information that will enable direct service providers to better assist families in the area of feeding, although it is not likely to be a direct benefit to you or your child. To thank you for your participation in the study, I will bring a small gift for your child. I will also provide you a summary of the research results after the study is completed, if you would like a copy. Your Birth-to-Three provider agency has agreed to ask for your participation in this study, but this study being conducted by me under the direction of my advisors at UCONN.

Throughout the study, I will make every effort to assure that you are comfortable with participation; however, if at any time you wish to withdraw from the study, you are free to do so. I will be glad to share the results of the study or answer your questions at any time. I would greatly appreciate your participation. If you would like to be part of this study, please indicate your consent below and provide your signature. Any questions regarding this project should be directed to John Pagano at (203) 294-0465. Thank you very much for your consideration.

Sincerely,

John Pagano, MS, OTR/L

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Parent Perspectives on Feeding

Informed Consent

I, _____, hereby consent to my participation in the following research project: Parent Perspectives on Feeding Their Child. John Pagano, MS, OTR/L, Researcher. School of Family Studies, University of Connecticut.
I give permission for developmental and medical information to be gathered from my child's Birth-to-Three record, and will participate in completing demographic and feeding questionnaires and a questionnaire regarding parenting stress. I understand that I am free to withdraw consent and to discontinue participation in the project at any time without prejudice.

_____ _____

Parent/Guardian Date

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Appendix H: Parent Perspectives on Feeding
Informed Consent and Release of Medical Information

Dear Parents,

I am an Occupational Therapist who has worked closely with the Birth-to-Three system for many years, providing services to children with feeding problems and their families. At the present time I am completing my Ph.D. at the University of Connecticut. As part of my dissertation project, I am requesting your participation in a research study that focuses on understanding parent's perspectives on feeding issues with infants and toddlers. My research project is titled *Parent Perspectives on Feeding.* I would appreciate the opportunity to visit with you at your home or the Birth-to-Three office to discuss feeding issues and have you fill out short questionnaires. All interviews will be confidential.

The questions will take approximately an hour. If you prefer, two visits can be arranged to complete the questions. I will ask you some basic questions about your family, then focus on your experience of feeding. The feeding questions will ask you to describe what feeding is like for you, and ask you to rate certain specific aspects of feeding. Following these questions, I will ask you to fill out a short questionnaire about your overall stress related to parenting. In addition to visiting you to ask for your views, I will gather information from your child's Birth-to-Three records regarding his or her developmental and medical status and Birth-to-Three treatment goals. The file will not be taken out of the office. All information from your child's Birth-to-Three records and the interview will be identified by a number and kept confidential.

I realize that answering questions during a home visit will take some time and effort on your part, and I thank you in advance for considering participation. I hope that this study will provide information that will enable direct service providers to better assist families in the area of feeding, although it is not likely to be a direct benefit to you or your child. To thank you for your participation in the study, I will bring a small gift for your child. I will also provide you a summary of the research results after the study is completed, if you would like a copy. Your Birth-to-Three provider agency has agreed to ask for your participation in this study, but this study being conducted by me under the direction of my advisors at UCONN.

Throughout the study, I will make every effort to assure that you are comfortable with participation; however, if at any time you wish to withdraw from the study, you are free to do so. I will be glad to share the results of the study or answer your questions at any time. I would greatly appreciate your participation. If you would like to be part of this study, please indicate your consent below and provide your signature. Any questions regarding this project should be directed to John Pagano at (203) 294-0465. Thank you very much for your consideration.

Sincerely,

John Pagano, MS, OTR/L

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Parent Perspectives on Feeding

Informed Consent

I, _____, hereby consent to my participation in the following research project: Parent Perspectives on Feeding Their Child. John Pagano, MS, OTR/L, Researcher. School of Family Studies, University of Connecticut.
I give permission for developmental and medical information to be gathered from my child's Birth-to-Three record, and will participate in completing demographic and feeding questionnaires and a questionnaire regarding parenting stress. I understand that I am free to withdraw consent and to discontinue participation in the project at any time without prejudice.
I also request that my child's birth-to-three provider agency release information regarding my child's developmental and medical status and Birth-to-Three treatment goals to John Pagano. I understand that he will keep this information confidential, and will receive a copy of information from my child's file and/or review my child's birth-to-three file, but will not remove the birth-to-three file from the office.

_____ _____

Parent/Guardian Date

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Appendix I: Reliability Information

I1. Categorizations of Diagnoses

The researcher developed hierarchical categorizations for the diagnoses of the target children based on the literature and his clinical experience as a pediatric occupational therapist. The categorizations were checked for reliability by Michelle Broggi, RPT, Physical Therapist and doctoral student in the Family Studies program at the University of Connecticut. The researcher and Ms. Broggi agreed on the diagnostic categories for 28 of the 31 subjects. Consensus was reached for the three diagnoses which had been categorized differently by 1) stressing that the categorizations were hierarchical and diagnoses would be placed in the first sequential diagnostic category that applied 2) adding to the developmental disabilities category "and language disorders", clearly identifying language disorder as a developmental disability, and 3) assigning hypotonicity to the prematurity categorization and removing it from the categorization of Cerebral Palsy (based on the literature indicating that low muscle tone is most frequently associated with prematurity, while high muscle tone is more indicative of Cerebral Palsy).

I2. Categorizations of Parents' Responses to the Open-Ended Questions

Responses to all of the open-ended questions were categorized by the researcher. The categories were then used by Sally O'Brien, certified special education teacher, to blindly assign the initial responses to categories. Comparison was made between the categorizations, and differences in categorization were resolved by consensus between the researcher and Ms. O'Brien. Consensus was reached through discussion, modifying or adding categories as indicated.

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I3. What are your greatest concerns regarding feeding your child?

Sally O'Brien and the researcher's categorizations agreed for 37 of the 57 items. The 20 disagreements in categorizing the items were resolved through consensus to use 3 of the categorizations initially proposed by the researcher, 6 initially proposed by Ms. O'Brien, 2 by revising the initial categorizations, and 9 by using new categorizations. Modifications made were revising the category limited diet parent can offer to limited diet variety, adding ambiguous to the category ambiguous/other, and adding liquid orally to the category child getting adequate nutrition/vitamins/calories/liquid orally. New categories were vomiting or reflux, persistence of eating problems, and feeding tube concerns.

I4. What do you find most frustrating in feeding your child?

Sally O'Brien and the researcher's categorizations agreed for 40 of the 55 items. The 15 disagreements in categorizing the items were resolved through consensus to use 3 of the categorizations initially proposed by the researcher, 3 initially proposed by Ms. O'Brien, 3 by revising the initial categorizations, and 6 by using new categorizations. Modification was made adding ambiguous to the category ambiguous/other. New categories were limited types of foods can give child and child not taking enough food.

I5. What if any areas of feeding your child do you need help with?

Sally O'Brien and the researcher's categorizations agreed for 32 of the 50 items. The 18 disagreements in categorizing the items were resolved through consensus to use 7 of the categorizations initially proposed by the researcher, 1 initially proposed by Ms. O'Brien, 6 by revising the initial categorizations, and 4 by using new categorizations.

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Modification was made adding ambiguous to the category ambiguous/other, and revising the category enjoying or accepting foods to child accepting a variety of foods and/or new foods. New categories added were many or all aspects of feeding and integrating strategies to improve feeding skills into the family routines.

I6. What if any areas of feeding your child do you need help with?

The alternate categorization of areas of feeding parents needed help with was suggested by Dr. Ronald Sabatelli, Associate Dissertation Advisor. Dr. Sabatelli did the original categorizations. Reliability was confirmed by the primary researcher. However, this is the only open-ended question reliability process in which the second person was already aware of the initial coding of responses.

I7. What aspects of feeding do you find most rewarding?

Sally O'Brien and the researcher's categorizations agreed for 42 of the 55 items. The 13 disagreements in categorizing the items were resolved through consensus to use 3 of the categorizations initially proposed by the researcher, 1 initially proposed by Ms. O'Brien, 8 by revising the initial categorizations, and 4 by using new categorizations. Modification was made adding ambiguous to the category ambiguous/other. The new category added was child's weight gain.

I8. What impact did Birth-to-Three feeding treatment have?

Sally O'Brien and the researcher's categorizations agreed for 19 of the 26 items. The 7 disagreements in categorizing the items were resolved through consensus to use 1 of the categorizations initially proposed by the researcher, 3 initially proposed by Ms. O'Brien, and placing 3 responses in the new categorization ambiguous.

I9. Categorizing the match of parents' goals with the goals in their child's chart

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Consideration was given to the match between the parents' feeding goals and the combined feeding goals in their child's chart. For the first parent goal 18 families described feeding goals and had goals from the child's chart available. Sally O'Brien and the researcher's categorizations agreed for 11 of the 18 responses. The 7 disagreements in categorizing were resolved through consensus to use 4 of the categorizations initially proposed by the researcher, 2 initially proposed by Ms. O'Brien, and 1 using the new categorization of Partially addressed.

For the second parent goal, there were 9 responses with corresponding chart data available. Both evaluators agreed on 5 of the 9 categorizations. The 4 disagreements in categorizing were resolved through consensus to use 1 of the categorizations initially proposed by the researcher, 1 initially proposed by Ms. O'Brien, and 2 using the new categorization of Partially addressed.

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Appendix J: Supplemental Tables

Table 1

Number and Percent of Parents Who Mentioned Each Feeding Problem

Feeding Problem	N	Never 0	Up to 25% of time 1	Up to 50% of time 2	Up to 75% of time 3	More than 75% of time 4	More than 50% of time 3 or 4
1.Lacking postural control for eating	30	20 (66.7%)	2 (6.7%)	2 (6.7%)	0	6 (20%)	6 (20%)
2.Lacking adequate movement for eating	31	15 (48.4%)	8 (25.8%)	2 (6.5%)	3 (9.7%)	3 (9.7%)	6 (19.4%)
3.Chokes on food	31	9 (29.0%)	16 (51.6%)	2 (6.5%)	1 (3.2%)	3 (9.7%)	4 (12.9%)
4.Eats too slow	31	12 (38.7%)	7 (22.6%)	4 (12.9%)	1 (3.2%)	7 (22.6%)	8 (25.8%)
5.Takes too long to feed	29	12 (41.4%)	6 (20.7%)	4 (13.8%)	2 (6.9%)	5 (17.2%)	7 (24.1%)
6.Refuses eating enough	31	7 (22.6%)	6 (19.1%)	3 (9.7%)	3 (9.7%)	12 (38.7%)	15 (48.4%)
7.Refuses drinking enough	31	19 (61.3%)	3 (9.7%)	1 (3.2%)	3 (9.7%)	5 (16.1%)	8 (25.8%)
8.Refuses food unless distracted	30	13 (43.3%)	4 (13.3%)	4 (13.3%)	0	9 (30%)	9 (30%)
9.Refuses age appropriate food textures	30	9 (30%)	1 (3.3%)	4 (13.3%)	5 (16.7%)	11 (36.6%)	16 (53.3%)
10.Spits out food	30	8 (26.7%)	10 (33.3%)	3 (10.0%)	3 (10.0%)	6 (20.0%)	9 (30%)
11.Eats too quickly	31	26 (83.9%)	2 (6.5%)	0	3 (9.7%)	0	3 (9.7%)
12.Eats too much	31	31 (100%)	0	0	0	0	0
13.Stuffs mouth	31	18 (58.1%)	6 (19.4%)	0	3 (9.7%)	4 (12.9%)	7 (22.6%)
14.Pica	31	27 (87.1%)	3 (9.7%)	0	0	1 (3.2%)	1 (3.2%)
15.Crying during meals	31	12 (38.7%)	10 (32.3%)	2 (6.5%)	4 (12.9%)	3 (9.7%)	7 (22.6%)
16.Wheezing	31	26 (83.9%)	3 (9.7%)	1 (3.2%)	1 (3.2%)	0	1 (3.2%)

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Table 2

Parent Ratings of Frustration Regarding Feeding Problems: Frequency and Percent

		Not Frustrating				Extremely Frustrating	
Feeding Problem	N	0	1	2	3	4	3 or 4
1.Lacking postural control for eating	10	0	3 (30%)	1 (10%)	3 (30%)	3 (30%)	6 (60%)
2.Lacking adequate movement for eating	16	1 (6.3%)	3 (18.8%)	3 (18.8%)	4 (25%)	5 (31.3%)	9 (56.3%)
3.Chokes on food	22	4 (18.2%)	3 (13.6%)	2 (9.1%)	5 (22.7%)	8 (36.3%)	13 (59%)
4.Eats too slow	19	3 (15.8%)	5 (26.3%)	4 (21.1%)	5 (26.4%)	2 (10.5%)	7 (36.9%)
5.Takes too long to feed	16	0	2 (12.6%)	6 (37.5%)	6 (37.5%)	2 (12.5%)	8 (50%)
6.Refuses eating enough	21	2 (9.5%)	0	2 (9.5%)	5 (23.8%)	12 (57.1%)	17 (80.9%)
7.Refuses drinking enough	11	2 (18.2%)	1 (9.1%)	0	0	8 (72.7%)	8 (72.7%)
8.Refuses food unless distracted	17	6 (35.3%)	4 (23.5%)	2 (11.8%)	2 (11.8%)	3 (17.6%)	5 (29.4%)
9.Refuses age appropriate food textures	21	2 (9.5%)	1 (4.8)	6 (28.6%)	7 (33.3%)	5 (23.8%)	12 (57.1%)
10.Spits out food	21	3 (14.3%)	3 (14.3%)	3 (14.3%)	3 (14.3%)	9 (42.9%)	12 (57.2%)
11.Eats too quickly	5	2 (40%)	1 (20%)	1 (20%)	0	1 20	1 (20%)
12.Eats too much	0	-	-	-	-	-	-
13.Stuffs mouth	13	4 (30.8%)	3 (23.1%)	3 (23.1%)	2 (15.4%)	1 (7.7%)	3 (23.1%)
14.Pica	4	1 (25%)	1 (25%)	1 (25%)	0	1 (25%)	1 (25%)
15.Crying during meals	19	1 (5.3%)	1 (5.3%)	2 (10.6%)	2 (10.6%)	13 (68.4%)	15 (79%)
16.Wheezing	5	1 (20%)	1 (20%)	1 (20%)	0	2 (40%)	2 (40%)

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Table 3

Problem Intensity 1: Frequency and Percent

Feeding Problem	N	0	1-4	5-8	9-12	13-16	9-16	M	SD
1.Lacking postural control for eating	30	20 66.7	4 (13.3%)	2 (6.7%)	3 (10%)	1 (3.3%)	4 (13.3%)	2.63	4.72
2.Lacking adequate movement for eating	31	16 (51.6%)	8 (25.1%)	3 (9.7%)	3 (9.7%)	1 (3.2%)	4 (12.9%)	2.84	4.17
3.Chokes on food	31	13 (41.9%)	12 (38.7%)	3 (9.7%)	1 (3.2%)	2 (6.5%)	3 (9.7%)	3.13	4.40
4.Eats too slow	30	15 (50%)	9 (30.1%)	2 (6.7%)	2 (6.7%)	2 (6.7%)	4 (13.4%)	3.13	4.85
5.Takes too long to feed	28	12 (42.9%)	7 (24.9%)	3 (10.7%)	4 (14.3%)	2 (7.1%)	6 (21.4%)	3.96	5.23
6.Refuses eating enough	27	8 (29.6%)	5 (18.5%)	2 (7.4%)	3 (11.1%)	9 (33.3%)	12 (44.4%)	7.20	6.92
7.Refuses drinking enough	30	21 (70%)	2 (6.6)	0	3 (10%)	4 (13.3%)	7 (23.3%)	3.53	6.16
8.Refuses food unless distracted	30	19 (63.3%)	6 (20%)	1 (3.3%)	1 (3.3%)	3 (10%)	4 (13.3%)	2.70	5.23
9.Refuses age appropriate food textures	30	11 (36.7%)	5 (16.6%)	3 (10%)	6 (20%)	5 (16.7%)	11 (36.7%)	6.13	6.06
10.Spits out food	29	11 (37.9%)	8 (27.4%)	2 6.8	3 (10.3%)	5 (17.2%)	8 (27.5%)	4.98	6.20
11.Eats too quickly	31	28 (90.3%)	1 (3.2%)	1 (3.2%)	1 (3.2%)	0	1 (3.2%)	.61	2.38
12.Eats too much	31	-	-	-	-	-	-	-	-
13.Stuffs mouth	30	22 (73.3%)	3 (9.9%)	2 (6.7%)	2 (6.7%)	1 (3.3%)	3 (10%)	1.97	4.23
14.Pica	31	28 (90.3%)	2 (6.4%)	1 (3.2%)	0	0	0	.42	1.59
15.Crying during meals	31	13 (41.9%)	10 (32.3%)	2 (6.4%)	4 (12.9%)	2 (6.5%)	6 (19.4%)	4.06	5.13
16.Wheezing	31	27 (87.1%)	3 (9.6%)	0	1 (3.2%)	0	1 (3.2%)	.61	2.26

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Table 4

Problem Intensity 2: Frequency and Percentages

Feeding Problem	N	0	1-4	5-8	9-12	13-16	9-16	M	SD
1.Lacking postural control for eating	10	0	4 (40.0%)	2 (20.0%)	3 (30.0%)	1 (10.0%)	4 (40%)	7.90	5.04
2.Lacking adequate movement for eating	16	1 (6.3%)	8 (50.0%)	3 (18.8%)	3 (18.8%)	1 (6.3%)	4 (25.1%)	5.50	4.38
3.Chokes on food	22	4 (18.2%)	12 (34.5%)	3 (13.6%)	1 (4.5%)	2 (9.1%)	3 (13.6%)	4.45	4.66
4.Eats too slow	19	4 (21.1%)	9 (47.3%)	2 (10.6%)	2 (10.6%)	2 (10.6%)	4 (21.2%)	4.95	5.33
5.Takes too long to feed	16	0	7 (43.8%)	3 (18.8%)	4 (25.1%)	2 (12.5%)	6 (37.6%)	6.94	5.22
6.Refuses eating enough	21	2 (9.5%)	5 (23.8%)	2 (9.6%)	3 (14.3)	9 (42.9%)	12 (57.2%)	9.62	6.36
7.Refuses drinking enough	11	2 (18.2%)	2 (18.2%)	0	3 (27.3%)	4 (36.4%)	7 (63.7%)	9.64	6.74
8.Refuses food unless distracted	17	6 (35.3%)	6 (35.3%)	1 (5.9%)	1 (5.9%)	3 (17.6%)	4 (23.5%)	4.76	6.25
9.Refuses age appropriate food textures	21	2 (9.5%)	5 (23.8%)	3 (14.3%)	6 (28.6%)	5 (23.8)	11 (52.4%)	8.76	5.38
10.Spits out food	18	0	8 (44.5%)	2 11.2	3 (16.7%)	5 (27.8%)	8 (44.5%)	8.06	6.10
11.Eats too quickly	5	2 (40.0%)	1 (20%)	1 (20%)	1 (20%)	0	1 (20%)	3.80	5.22
12.Eats too much	0	-	-	-	-	-	-	-	-
13.Stuffs mouth	13	4 (30.8%)	4 (30.8%)	2 (15.4%)	2 (15.4%)	1 (7.7%)	3 (23.1%)	4.62	5.49
14.Pica	4	1 (25.0%)	2 (50.0%)	1 (25.0%)	0	0	0	3.25	3.59
15.Crying during meals	19	1 (5.3%)	10 (52.7%)	2 (10.6%)	4 (21.1%)	2 (10.5%)	6 (31.6%)	6.63	5.09
16.Wheezing	5	1 (20.0%)	3 (60.0%)	0	1 (20.0%)	0	1 (20.0%)	3.80	4.82

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Table 5

Frequency Ratings for Positive Feeding Behaviors

	Never Occurs	Up to 25% of time	Up to 50% of time	Up to 75% of time	More than 75% of time	More than 50% of time
Positive Feeding Behaviors	0	1	2	3	4	3&4
1.Accepting touch on the face for wiping	5 (16.7%)	4 (13.3%)	6 (20%)	2 (6.7%)	13 (43.3%)	15 (50%)
2. Accepting touch of the spoon	2 (6.5%)	3 (9.7%)	4 (12.9%)	4 (12.9%)	18 (58.1%)	22 (71%)
3.Chewing in an age appropriate way	15 (50%)	1 (3.3%)	6 (20%)	0	8 (26.7%)	8 (26.7%)
4.Opening mouth for spoon	3 (9.7%)	3 (9.7%)	6 (19.1%)	3 (9.7%)	15 (50%)	18 (59.7%)
5.Taking food off spoon with lips	7 (24.1%)	3 (10.3%)	2 (6.9%)	5 (17.2%)	12 (41.4%)	17 (58.6%)
6.Keeping food in mouth while eating	1 (3.2%)	0	5 (16.1%)	7 (22.6%)	18 (58.1%)	25 (80.7%)
7.Drinking in an age appropriate way	11 (35.5%)	1 (3.2%)	4 (12.9%)	1 (3.2%)	14 (45.2%)	15 (48.4%)
8.Sitting long enough to complete meal	3 (9.7%)	4 (12.9%)	3 (9.7%)	2 (6.5%)	19 (61.3%)	21 (67.8%)

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