NOT AT THE TABLE:
AN ETHNOGRAPHY OF FEEDING CHILDREN
BY GASTROSTOMY TUBE

by

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A thesis submitted in conformity with the requirements for the degree of M.Sc.
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Gastrostomy feeding, a nutrition intervention, has recently begun to be used in a pediatric population. This intervention has been efficacious in correcting undernutrition and minimizing the risk of aspiration in children with feeding impairments associated with neurodevelopmental impairments. However, anecdotal accounts indicate that families are ambivalent about the initiation of g-tube feeding in these children, in spite its physiologic benefits. In order to develop a broader understanding of the effects of g-tube feeding on children and their families, a critical ethnography was conducted. The mealtime contexts of eight children with neurodevelopmental impairments who were fed by g-tube were explored. Findings indicated that families attempted to normalize the feeding/eating activities of their children within structural constraints. Although mealtimes were constructed with children's well-being in mind, they sometimes placed children at physical risk and demanded tremendous sacrifices on the part of parents.
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1. INTRODUCTION

Approximately one third of children with cerebral palsy have a level of central nervous system involvement which manifests itself in varying degrees of feeding impairment (Zeman, 1991). This impairment can involve either the voluntary or involuntary phases of the swallow, leaving children at risk for undernutrition and/or aspiration and their consequences. Over the past decade and a half the health professions have made efforts to characterize the altered aspects of the impaired swallow, to develop rehabilitation techniques to improve the swallow, to improve non-oral feeding techniques, and to address the physical consequences of a feeding impairment. While progress in all these areas has been difficult and sometimes controversial, efforts to address children's undernutrition and aspiration may have had significant effects on the lives of both the children and their families. This may be especially true when interventions change the way children are fed.

One such intervention is gastrostomy tube feeding. Gastrostomy feeding usually leads to improvement in children's physiologic well-being. However, little is known about how gastrostomy feeding affects the social life of children and their families. In particular, there is limited information about how gastrostomy feeding is integrated into children's day to day routines.

In Canada over the past several years there have been at least four attempted or actual "mercy killings" of severely disabled children by their parents. In reports of these incidents, the media have described the children's need for gastrostomy feeding as part of an "inhuman" and "inhumane" existence. Gastrostomy feeding is offered as part of the rationale to end children's lives. Although this is an extreme reaction, this view of gastrostomy feeding is rarely even alluded to among medical
accounts of the challenges children and their families may face with this intervention.

Among scholars in the field of disability studies, there has been a contention that disability rests at the intersection between individual functional impairment and the environments in which individuals live. Individual impairments become disabling as factors in the environment impede a person's ability to participate in everyday life. This suggests that before we can appreciate the impact of gastrostomy feeding on the lives of children and their families, we need to recognize how its implementation is influenced by or influences the environment or context in which children are fed.

In this thesis an ethnographic approach is used to gain insight into the mealtime context of children who use gastrostomy tubes. A sample of eight children with neurodevelopmental impairments was recruited through a feeding assessment clinic in a large Canadian city. Children were observed during their mealtimes on several occasions in order to develop a picture of their immediate social and physical environments. Interviews conducted with at least one parent of each of these children provided a broader perspective on the mealtime context. The socio-cultural context in which the children lived was comprised of two mutually constitutive components. Children lived in a discursive context which strongly emphasized community integration, family based care, and normalcy. Linked to this were practices, which enacted and maintained various threads of these discourses. Practices took place both at the level of public institutions and within the family.

As an understanding of the mealtime environment of children develops, we should also develop a deeper understanding of children's disability. The picture of
mealtimes that develops is a microcosm of children's overall environment. In a sense, we could use any activity, such as playtime, school attendance or personal hygiene activities, to arrive at similar insights. These insights, together with our substantial understanding of the functional aspects of feeding impairments, may have implications in furthering our assessment of effectiveness of interventions such as gastrostomy feeding. In particular, we may be able to understand how the effectiveness of interventions such as gastrostomy feeding are affected by its potential to be part of an environment which "creates" disability.
2. REVIEW OF RELEVANT LITERATURE

This chapter reviews some of the background and relevant literature to the issue of gastrostomy feeding in children with severe disabilities. In this section I have attempted to pull together a variety of perspectives on the feeding experience of children. The review begins with literature about the feeding experience of children from the perspective of nutritional anthropology. Medical literature, regarding the origin and consequences of feeding impairments, as well as the use and clinical evaluation of gastrostomy, in the pediatric population with neurodevelopmental impairments, is then presented. Finally, the research question is framed in light of my personal experience in this area, and social science literature from disability and childhood studies.

2.1 The Feeding Experience in Children

Feeding and eating offer children an opportunity for nourishment and being nurtured. They provide children with their first chance to interact with the external world (Lupton, 1996). The feeding experience allows children to exercise autonomy and control, and to develop their identities. Yet, all children may face unique challenges throughout their feeding experience. As Ellen Satter (1990) suggests, feeding children requires a balance between meeting their physiologic and growth needs, while recognizing that feeding is also essential for children's psycho social development. Satter describes three main stages where these two concerns overlap. The first is "homeostasis" where infants try to integrate neurophysiologic functions and reactions to interaction with the outside world. Throughout this stage, the parent has certain obligations to shape feeding into a behavioral and social organizer for their newborn infant. Caregivers try to respond quickly to feeding cues. They initiate and aid the feeding process. During the second or "attachment" stage, at 3 to
7 months, the child "falls in love" with his or her primary caregiver, and is able to purposively interact with the surrounding world. The caregiver continues to learn and respond to the child's cues for feeding, giving the child increasing control. Satter suggests that feeding interactions become more apparently emotionally laden. Each action becomes imbued with meaning that may lead to future difficulty. The final stage, that one could argue continues for many years, is "separation and individuation". After children reach their first year of life, they begin to develop a more complex sense of self, which parallels their increasing neuromuscular development. Children strive to control their bodies and simultaneously become more autonomous.

Satter is most concerned with the success of the feeding interaction, however her analysis calls our attention to the multiple layers of meaning associated with feeding and eating. The act of eating becomes laden with personal, social, cultural and even political significance. Children's feeding and mealtimes are filled with "taken for granted" meanings for both children and those around them. For children, feeding and mealtimes become imbued with meanings related to independence, autonomy, control (Birch et al, 1995; Counihan, 1990). For caregivers, feeding may similarly become related to control and independence, but also a forum for defining the caring work one performs (e.g. Spalding, 1992; Charles and Kerr, 1988; DeVault, 1991).

Food itself carries a complex set of meanings, based in part on its primary characteristics such as colour, texture and taste. It also derives meaning from both its method of preparation or presentation and by the manner in which it is served (Counihan and Van Esterik, 1997). Much of the meaning that food has in North American culture stems from its perceived consequences on the body (Heldke and Curtin, 1992; Barthes, 1979). In her analysis of the food journals of her anthropology
students, Counihan (1990) found that the students' writing carried a powerful belief that what and how one eats in North America defines who one is, both to oneself and to others. What and how one eats communicates self-control, gender and attractiveness, both in terms of the consequences it has on the body and in the actual act of eating.

Allison James' (1994) qualitative study of British schoolchildren's sense of self and identity illustrate how Counihan's findings are evident even from a very young age. Physical tasks such as eating had significant personal meanings for children, as increased physical capacity and control broadened their phenomenological understanding of the world. Eating the same foods as their peers took on increased importance as children understood that their physical activities often defined who they were to others. One girl with celiac disease found herself excluded during lunch hours until her mother began to use gluten free bread so she could bring a sandwich like other children. Snack foods, such as potato chips, signified maturity and independence, particularly if they were purchased by children themselves. James provides examples of how children attempted to hide items of food that would have sent "uncool" meanings to their peers. For example, one boy experienced distress over the French vanilla yogurt his mother kept including in his lunch, since for his classmates it was associated with femininity. His classmates brought Mr. Man yogurt, a product targeted at children, particularly boys, that was viewed as a more appropriate alternative.

The work described above is still relatively recent and does not provide a clear indication of how the feeding experience is influenced when feeding is physiologically impaired. This next section will examine the characteristics of the feeding experience for children with neurodevelopmental disabilities with a subsequent feeding impairment.
2.2 The Feeding Experience in Children with Neurodevelopmental Impairments

In one of the earliest efforts to characterize the nutritional status and feeding challenges of children with neurodevelopmental impairments, Ruby and Matheny (1962) suggested three problems faced by children who had oral motor involvement. These included an increased amount of time required for eating, lower intake and increased fatigue throughout the eating process. Later studies confirmed these suspicions and demonstrated how the three challenges were often interrelated, exacerbating one another.

2.2.1 Definition of oral motor impairment

The physiological definition of oral motor impairment may be helpful in appreciating its effect on the feeding experience. The swallow can be divided into two phases, the voluntary and involuntary phase (Gisel et al, 1995; Arvedson et al, 1991; Jones, 1989). In the voluntary phase, food is placed into the mouth, then masticated, savoured and manipulated into a bolus. The bolus is propelled by the tongue and passes the anterior faucal arches and the swallow reflex is triggered. At this point the involuntary stage of the swallow is initiated and progresses through several steps. First, the soft palate elevates to close the nasopharynx. Next, peristalic movement passes the bolus through the pharynx. The larynx is then elevated to close on the epiglottis, which has moved downward to protect the true and false vocal cords. Finally, there is a relaxation of the cricopharyngeal sphincter in order to allow the bolus to pass into the esophagus. In general, children with severe and multiple neurodevelopmental impairments tend to demonstrate three major abnormalities (Jones, 1989). They tend to have poor lingual function, delayed swallowing initiation and poor pharyngeal peristalsis. In turn, there are three major consequences for children's feeding and eating experience. First, children have slow oral transit time. Second, children demonstrate poor bolus formation,
with food falling out of the mouth or escaping into the pharynx before the swallow reflex is initiated. Finally children display poor pharyngeal transit time, giving rise to high amounts of pharyngeal residue. These characteristics of an oral motor impairment translate into a oral feeding experience that can be burdensome for both the child and caregiver, as well as placing the child at physical risk for undernutrition and aspiration.

2.2.2 Increased Time

Ruby and Matheny's claim that more time is required to feed the child with cerebral palsy has strong empirical and statistical support in the literature. Johnson and Dietz (1985) were among the first to note that caregivers spent disproportionate amounts of time in feeding their children with disabilities. Spalding (1992) described mothers' experiences of feeding their disabled children prior to gastrostomy tube insertion. In an especially dramatic account, one mother described feeding her infant with an eyedropper over a 20 hour period each day. Reilly and Skuse (1992) conducted a preliminary survey to study the eating patterns of a small sample of children who were at high risk of disordered feeding due to oral motor dysfunction. The study also offered the opportunity to observe the normal feeding practices of the children's caregivers within their own homes. They observed 12 children ranging in age from 15 to 39 months and constructed a comparison group, matched pair-wise with age, sex and race. Semi-structured interviews of mothers regarding past and present feeding practices, details of past feeding difficulties and interventions sought, were conducted. The main meal of the day was also video recorded. Comparison of mealtime lengths between the control and study group indicated no significant differences. However, caregivers of the children with oral-motor dysfunction reported that mealtimes were often interrupted by excessive coughing, choking, gagging and serious vomiting, events which would presumably lengthen the amount of time to complete a meal. As well, case children were
offered less food than comparison children in their meals, perhaps accounting for the similar feeding times. It was also not clear from the study whether children who had oral motor impairments ate smaller meals, more often, which would have required caregivers to dedicate a greater proportion of their day to feeding.

The longer time requirement for feeding has also been confirmed clinically. Gisel and Patrick (1988) studied seven children, ages 2 to 16 years with severe cerebral palsy, to describe and measure feeding efficiency. Their belief was that if some of the poor nutritional status experienced by children with severe disabilities was due to poor intake, then feeding time and effort would need to be increased to ensure greater intake. Both children's and feeders' actions and behaviours were monitored by video recorder. Each child received ten bites of both a pureed and a solid food. The results were compared to feeding efficiencies of weight age matched controls. Gisel and Patrick defined feeding efficiency as the time which lapsed between placement of food in the mouth and completion of the swallow. The mean time of 10 swallows was used for comparison with normal time. They found that feeding efficiencies of the children with cerebral palsy were far below those of the controls. There were of course some limitations with this study, mostly resulting from the control imposed upon the feeding situation. Children were all fed the same foods while sitting in their wheelchairs. It is possible that the increased time and evidence of problematic behaviours seen in this study reflect in part an uncomfortable or unfamiliar feeding situation. The investigators suggest that the comparison of participants with weight aged controls probably underestimated the severity of feeding impairment. A more appropriate comparison may have been to use developmental age controls. This also highlights the problems of comparing children when it is not clear whether every child in the study group was actually given developmentally appropriate foods. In spite of these problems, it is
noteworthy that all children with cerebral palsy required more time to eat, taking up to fifteen times longer in one case.

More recently, research attention has focused on "blueprinting" the characteristics of the dysfunctional swallow that contribute to the longer meal times, as well as other consequences associated with the feeding impairment. Casas and his colleagues (1994) compared the oral management of food and beverages of 20 children who were neurologically normal with 20 children who had cerebral palsy. They monitored the oral phase of deglutition by means of surface electromyographic recordings of the masseter and infrahyoid muscles. They also were able to monitor respiratory coordination with respiratory inductance plethysmographic recordings. Children were observed throughout three tasks: a sip swallow in which they sipped a 5 ml volume of liquid, a continuous swallow in which children swallowed a 75 ml volume and a cookie task in which children ate a bite of a cookie. Casas and his colleagues found that children with cerebral palsy took significantly longer in the ventilatory prep phase of the swallow where they adjusted their breathing to accommodate the upcoming cup, as well as taking a longer time from the time the cup touched their lip to the time they initiated a swallow. The investigators found that children with cerebral palsy altered their ventilatory phase earlier and took a longer time for ventilatory recovery after the swallow. In fact the entire time from preparation to recovery took longer for children with cerebral palsy. The continuous swallow task showed very similar results, although faced with this larger task, children spent longer preparing and taking the liquid into their mouth. The cookie task showed no significant differences between the two groups. In summary, the time of intervals for children with cerebral palsy took longer and demonstrated more variation. The results suggested that children with cerebral palsy required more time for bolus preparation to recover baseline ventilatory pattern after liquid tasks. It also appeared that children handled smaller amounts of
liquids better than larger, continuously swallowed volumes, lengthening the time required to finish a beverage.

In another study, Casas and his colleagues (1995) compared the oral management and transport of solid and liquid food boluses between neurologically normal children and those with cerebral palsy. They wanted to determine the normal intervals of pre-oral and swallowing activity in the two groups of children. Using the sip-swallow and the cookie task, they found significant differences in feeding capability between neurologically normal children and those with cerebral palsy. Every interval of the oral swallow phase, as well as the total oral swallowing time, was significantly longer in children with cerebral palsy. While more time was required to handle solids, children with cerebral palsy tended to handle them better than liquids.

2.2.3 Lower Intakes
Given that there is often a limited amount of time which caregivers can dedicate to feeding, the longer time to feed children with an oral motor impairment means these children tend to have lower intakes than normal children. Lower intakes, however, are the result of a number of different factors. In an early assessment of children's eating ability and food intake, Hammond and his colleagues (1966) studied thirty one children with spastic and athetoid cerebral palsy, who ranged in age from seven to sixteen years. The purpose of their study was threefold. First, they wanted to evaluate the dietary intakes and to measure the nutritional status of the children. Second, they wished to determine the effect, if any, of motor, topographic, and functional capacity factors of cerebral palsy on children's nutritional status. Finally, they wanted to compare the effects of functional capacity factors of cerebral palsy and the apparent degree of mental retardation on nutritional status. They found the estimated nutrient consumption of over half the
participants failed to reach the 100% of the dietary allowances for calories, calcium, iron and thiamin. Perhaps of more concern, most intakes appeared higher for those with less arm involvement and higher IQ scores. The authors seemed to suggest in the study that self care skills may be implicated with this group. These children were in an institutional setting, therefore self feeding skills may have been helpful in increasing intake. The authors noted that children required prolonged periods of feeding and individual attention. They indicated that some children tired before completing their meals, given the long time required for feeding, thus reducing intake. Other children appeared to lose considerable amounts of food due to drooling, coughing, and inability to control mouth closure.

The difficulty children with oral motor impairments experience in attaining an adequate intake is highlighted in the study by Thommessen and his colleagues (1991). This Norwegian study examined the children's energy and nutrient intakes in relation to the presence or absence of feeding problems and alternative feeding practices offered to improve intakes, such as assisted feeding and feeding with pureed food. They compared the energy and nutrient intakes of 221 disabled children, aged 1 to 16 years, who had feeding problems and required alternative feeding practices, with those of disabled children without these problems. Researchers conducted interviews with parents regarding their food habits and feeding practices of their child. They also assessed children's dietary intake using four-day food records. The authors found that children who had oral motor dysfunction had significantly lower mean relative intake of energy than disabled children without these problems. A number of children had nutrient intakes below the 70% of the RDA, approaching the 66% mark which is associated with increasing risk of the physical consequences of undernutrition.
Bandini's (1991) comparative work with children with severe disabilities offers some reassurance regarding children's low intake. Her group studied total body water and extracellular water in 13 adolescents with cerebral palsy and 16 adolescents with myelodysplasia. Resting metabolic rate (RMR) and total energy expenditure (TEE) were measured in 19 of the 29 participants by indirect calorimetry and the doubly labeled water method. They found that RMR and TEE were significantly lower than that of the control group. This study suggested that the large energy intakes that had been advocated in the past (e.g. Ruby and Matheny, 1962) had perhaps overestimated this group's requirements. Instead the low body weights seen in the past were perhaps reflective of the difficulty in feeding children enough food. While this study helps us narrow our focus of concern, it highlights the difficulty children face in achieving even very small intakes, since even with potentially lower requirements they are not able to maintain weight or growth velocity.

2.2.4 Fatigue
The time required for children to eat often means they grow too tired to take in the energy they require (e.g. Thommessen, 1991). This reduced intake, compounded with the frustration of the feeding experience, may also contribute to a child's feelings of fatigue and irritability throughout a meal. Reilly and Skuse (1992), Thommessen and colleagues (1991) and Webb (1980) all noted that the foods offered to children with serious disabilities were quite limited, often bland and sometimes covered in a thick gravy, making everything look similar. In each of these studies the authors speculated that the monotonous quality of the foods offered to children may have played a part in the children's fatigue and early disinterest in their meal.

From a more physiologic perspective, Rogers, Arvedson, Msall and Demerath (1993) suggested that mealtime hypoxemia may have a role in children's boredom and
sleepiness during feeding. Using multiple case analyses of 5 children with CP, all with severe dysphagia, the authors used pulse oximetry throughout mealtimes to assess the impact of oral feeding different textures on their hemoglobin saturation. Pulse oximetry indicated that all of the cases experienced mealtime hypoxemia, ranging from mild to life-threatening. The authors suggested that changes implemented in feeding strategies were effective in increasing alertness and improving signs of overt fatigue. In one case the child required four hours less sleep a day and began to gain weight. The authors suggested that fatigue experienced throughout mealtimes, which in turn limited children's intake, could be the result of mealtime hypoxemia. As outlined at different points above, children with oral motor dysfunction may experience discoordinated breathing and aspiration. Repeated aspiration may impact lung function and capacity, leaving children at risk of low oxygen reserves. As a result, the difficulty these children experience in coordinating their breathing with deglutition may put them at increased risk for poor hemoglobin oxygen saturation, leading to their becoming easily fatigued.

2.3 Consequences of the Impaired Feeding Experience

2.3.1 Undernutrition

One of the major consequences of the lengthy time commitment, associated fatigue and limited intake which characterize their feeding experience is that these children present with poor nutritional status. While the measurement of nutritional status has always been problematic in this group, children are often visibly undernourished. In general, children have presented with reduced skinfolds, low weight, low weight for height and height age, and a marked decrease in linear growth (Stallings et al, 1993; Stallings et al, 1995; Spender et al; 1988).

One of the earliest characterizations of the nutritional status of children with neurodevelopmental impairments was offered by Ruby and Matheny (1962). They
observed the growth of 137 children with cerebral palsy, half boys and half girls, with an equal prevalence of athetoid and spastic forms of the condition. Prefacing their work, they noted the difficulty in obtaining accurate measures of nutritional status, such as height. Growth patterns followed along normal curves, however boys appeared to be approximately twelve to fifteen months below the 15th percentile. They also found that oral motor involvement was closely associated with poor food intake and that the extent of oral motor involvement and general growth closely paralleled one another. Since Ruby and Matheny conducted their study, children are able to survive with a greater degree of impairment, suggesting that, today, children might present with even poorer nutritional status than was seen in this study.

Spender and his co-workers (1988) presented data on American children with cerebral palsy collected during a nutritional assessment study. They measured 100 children of both sexes up to the age of 18 years. Children had various forms of CP, including quadriplegia, hemiplegia and diplegia, as well as several children with hypotonia or a movement disorder. The mean centripetal fat ratio (CFR) in children with cerebral palsy was 45.9%, a measure that was similar to that reported for chronically undernourished children. It was observed that there was a reduction of triceps fat without comparable reduction of subscapular fat in children with limb paralysis, including those in whom there was no arm involvement. This finding suggested chronic undernutrition, with fat retention around the torso.

### 2.3.2 Aspiration

Aspiration is often the impetus to implement gastrostomy feeding. Aspiration of foods into the airways is a serious consequence of oral motor dysfunction in children with disabilities (Gisel et al, 1995; Jones, 1989). Aspiration results in choking and coughing and lower respiratory tract infections. It can also cause acute
pneumonia and chronic lung changes associated with fibrosis. This tissue change decreases lung compliance and can bring about changes in intrathoracic and intraabdominal pressures, potentially aggravating gastroesophageal reflux, and further contributing to undernutrition.

Rogers' (1994) characterization of the swallowing difficulties of children with cerebral palsy illustrates the problems imposed by a feeding impairment. He studied 90 children with cerebral palsy between the ages 1 week to 22 years (average age was 7.5 +/- 6 years). The children had difficulties with the oral and pharyngeal phase of their swallow, both contributing to problems in airway protection. Seventy one percent of the participants were able to eat orally, another 24% had supplemental g-tube feeding, while the remaining 2% were fed solely by g-tube. Videofluoroscopic modified barium swallow (VBMS) studies revealed a number of abnormalities with deglutition. More than 90% of the children displayed poor tongue control, in the oral phase of their swallow, and therefore had difficulty managing the bolus. It was also evident that 83% of the children had a slow initiation of the swallow, requiring multiple swallows to clear the bolus from the mouth. Once the swallow was initiated, aspiration occurred in 38%, with most cases being silent aspirators. As expected, most children aspirated on liquids (96%), fewer aspirated on pureed textures (48% or 11 children) and the least aspirated on solid textures (24% or 6 children). Two features of the pharyngeal phase, pharyngeal residue and decreased pharyngeal peristalsis, were significantly associated with aspiration. Many children did not appear to have a "clean up swallow" after their first swallow to clear pooled residue out of the pharynx. Even if a clean up swallow was achieved, the swallow was too weak to effectively clear the residue. Food residue, remaining around the airway after a completed swallow, potentially enters the airway when children inspire. Aspiration appeared to occur before, during and after the swallow, suggesting that a number of problems with the swallow may work together to
contribute to entry of food into the airway. Rogers and his colleagues suggest that the inability to manage and quickly clear the bolus throughout the swallow, in addition to breathing that was poorly coordinated with the swallow, led to aspiration.

2.3.3 Summary
To date the feeding experience of children has been characterized in terms of the length of time required to feed children, the amount children eat and the level and cause of fatigue children experience throughout eating. The scientific community has sought to characterize these problems in a variety of ways, ranging from qualitative work done by Reilly and Skuse (1992) to the very precise mapping of oral transit time performed by Casas and his colleagues (1994; 1995). Unfortunately the feeding situation for these children follows a downward spiral. Indeed, as nutritional status declines, some children may experience an increase in spasticity, which further worsens oral motor impairment. This results in an even longer time requirement for eating, a further limitation in intake and even greater fatigue and irritability.

2.4 Nutrition interventions
In 1994, the Canadian Pediatric Society introduced clinical practice guidelines to address undernutrition in children with neurodevelopmental impairments specifically. The guidelines suggested a progression of options beginning with an alteration of feeding practices. Modified textured foods and oral motor rehabilitation are the preferred means of addressing undernutrition associated with a feeding impairment. If these strategies fail, implementation of enteral feeding is recommended.
Gastrostomy tube (g-tube) feeding involves the infusion of a nutritional formula directly into the stomach through a small bore tube. A polyvinyl tube is inserted directly through the abdominal and stomach wall, using either surgical, endoscopic or radiologic techniques (Zeman, 1991). Prior to the introduction of percutaneous endoscopic gastrostomy (PEG) techniques with local anesthetic, implementation of tubes was performed surgically or by laprotomy and required that children be given a general anesthetic. Recovery was often poor, and infection and gastric ulceration were common (Davidson et al, 1995). With PEG, many of these problems have been circumvented, enabling its use in a more medically fragile population. Depending on the degree of oral motor impairment, gastrostomy feeding can either supplement or completely replace oral intake.

2.4.1 Gastrostomy feeding outcomes
Gastrostomy feeding has been evaluated chiefly in terms of its physiologic impact. In general, gastrostomy feeding in children with neurodevelopmental impairments has demonstrated an improvement in their growth and development. Children have shown an increase in their weights and skinfold measures (Naureckas, Kaufer and Christorfell, 1994; Patrick and Gisel, 1986; Sanders et al, 1990; Rempel et al, 1988; Shapiro et al, 1986). However, similar increases in linear growth have not been seen. Early nutrition intervention will promote an increase in linear "catch-up" growth, however as evident in the study by Sanders and colleagues (1990), the more time that lapses from the original central nervous system insult, the less impact nutrition intervention will have on catch-up growth.

One of the challenges in evaluating gastrostomy feeding outcomes is that comparisons between these studies have been notoriously difficult. Studies have often used slightly different anthropometric measures and nomograms to assess nutrition status of the participants, although most examine some relationship
between weight and height. Anthropometric measures have been difficult to obtain; for example, accurate measurements of height are almost impossible with this population given the presence of contractures, spasticity or spontaneous movements. Skinfolds are similarly difficult to assess, since it is not certain if measurements reflect bone density, muscle tone or fat stores.

Another difficulty is that cerebral palsy, an umbrella diagnosis, brings together a heterogeneous group of symptoms (Bhushan, Paneth and Kiely, 1993; Hammond et al, 1968). Just as this means that feeding impairments manifest themselves differently in different children, it may also mean that nutrition status and other responses to nutrition intervention will also demonstrate wide variation.

This variation in response to gastrostomy feeding is evident in children's inconsistent outcomes. While there was often an improvement of the group's mean weight and weight for height ratio, some children actually experienced a reduction in these two measures (e.g. Shapiro et al, 1986; Patrick et al, 1988). At the other extreme, gastrostomy feeding has sometimes resulted in children becoming obese, a serious outcome, given the limited options children have for losing weight and the added physical energy which may be required for caregiving tasks. As well, a number of iatrogenic consequences associated with the implementation of gastrostomy feeding, including the exacerbation of gastroesophageal reflux and continuation of aspiration, cramping, stoma site infection, perforation of the abdomen, tube displacement and external leakage (Al Malki, et al., 1991; Davidson, Catto-Smith and Beasley, 1995; Gauderer, Olsen, Tellato and Dokler, 1988; Marin, Glassman, Schoen and Caplan, 1993).

As outlined earlier, oral feeding of children with neurodevelopmental impairments appears to be time consuming and possibly occurs within an emotional context of
frustration and fear for both caregiver and child. The Canadian Pediatric guidelines position gastrostomy feeding as potentially reducing the burdensome and frightening nature of orally feeding a child with a neurodevelopmental impairment. However, three studies exploring parental reactions to gastrostomy feeding have begun to illuminate the challenges and complexities involved in feeding a child via gastrostomy.

2.4.2 Family perceptions of gastrostomy feeding

Michealis, Warzak Stanek and Van Riper (1992) noted that there was a lack of literature addressing the concerns of families regarding the enteral feeding of their children in the home and school setting. To address this, the researchers asked 24 primary caregivers of children fed by gastrostomy tube to describe the difficulties they faced related to gastrostomy tube procedures and management. A list of problems was compiled and given to caregivers in order to assess how frequently they experienced each. Eleven pediatric feeding specialists were asked to judge how common and difficult they felt items from the same list were among their patients. Families varied in terms of the present age of the child, whether they attended school, the age of tube placement and the duration of tube feeding. Families encountered a wide range of difficulties related to their child’s use of a g-tube, however socially related problems appeared to be of significant concern. Among these problems, families identified finding a baby-sitter, dealing with the general public and a sense that their child was deprived of social activities, as their most important and frequently encountered problems. In contrast, professionals rated these issues of least importance, placing basic and medical care concerns much higher. The authors suggested this discrepancy between caregiver and professional rating of problems related to gastrostomy use could negatively impact on how well they worked together as a team to promote the efficiency and effectiveness of gastrostomy tube procedures. Their findings reflect the narrow focus of gastrostomy
evaluation and suggest that families may experience difficulties which professionals are both unaware of and unprepared to address.

Using a qualitative research design, Brotherson, Oakland, Scrist-Mertz, Litchfield and Larson (1995) explored families' concerns regarding the decision to initiate gastrostomy tube feeding in their children with severe disabilities. The researchers interviewed parents or major caregivers two to four times about quality of life issues related to their child’s feeding and mealtimes, both before and after the implementation of gastrostomy tube use. Although the themes which emerged in the data tended to be focused around the parental or caregiver decision making process, some information about the mealtime context emerges. Similar to findings by Michealis and her colleagues (1992), families in this study also found that the use of a g-tube was accompanied by a number of social problems. Families all found that their children were visibly better nourished, more alert and appeared happier after the initiation of g-tube feeding. However, many families expressed loss in addition to these benefits. Some families found that they lost caregiving support once the gastrostomy tube had been put in place. People who had helped them with their children's feeding prior to the use of the g-tube, were now intimidated by the technical nature of the new feeding method. Families also experienced a financial loss, given the high price of their child’s formula and feeding equipment. Families also perceived that their children lost an aspect of normalcy with the initiation of g-tube feeding, believing that their child’s disability was now more visible and that their mealtimes were bereft of "normal" dimensions, such as opportunities for interaction, nurturance and the enjoyment of food.

Canadian researchers, Thorne, Radford and McCormick (1997), also conducted a qualitative study to determine the meaning of long-term gastrostomy use in children with severe disability. They interviewed sixteen nurses and seven parents
about quality of life issues related to gastrostomy feeding. Each of the parents had several years' experience in feeding their children via gastrostomy. Many of their reported findings related the meanings of gastrostomy feeding that arose for both parental and professional caregivers when they were initially considering the implementation of g-tube feeding for a child. Two positive meanings were present, "ending the struggle" related to oral feeding and "caregiver convenience" related to the relief gastrostomy was supposed to provide. However, as in the study by Brotherson and her colleagues (1995), many of the meanings related to loss. Families and nurses felt that the implementation of gastrostomy feeding symbolized the abandonment of hope, the relinquishing of the opportunity for the child to be normal, and maternal failure. Once gastrostomy feeding had been established, it was less clear what it symbolized to parents. Once again parents were pleased with the positive physical outcomes for their children. However parents still had some ambivalence related to gastrostomy feeding. They were concerned that it created body image problems for children and diminished their opportunity for social interaction. The authors also allude to a range of mealtime activities which were performed in addition to using the gastrostomy to feed their child. Unfortunately the authors do not explore this to any great degree.

These three studies clearly indicate that gastrostomy feeding has implications for families beyond its physiologic effect on the child's health. Gastrostomy feeding appears to have a social impact on the day to day life of families. As well, there appear to be a number of symbolic meanings surrounding the use of gastrostomy, which may affect the opinions and actions of the very people who are responsible for integrating it into children's mealtime context. Many of the findings of the two qualitative studies focused on the decision making process around the implementation of gastrostomy feeding. However Thorne et al's description of the aftermath of the implementation of gastrostomy feeding highlights different
concerns than those around the decision making process. As well, the finding from Michealis and her colleagues (1992) suggest that the duration of children's gastrostomy use made no significant difference on the types of problems parents encountered. This suggests that experiences surrounding gastrostomy use may continue for many years. Therefore the concerns families experience related to gastrostomy feeding may have a long and lasting impact on how effectively gastrostomy is used in children's day to day routines and mealtime context.

2.5 Reconsidering the impact of gastrostomy feeding: A personal perspective

A number of media stories have highlighted how some families of children with severe disabilities have found themselves taking extreme measures to alleviate their children's, and perhaps their own, suffering. (Jenish, 1994; Findlay, 1997; Saunders, 1998). In each of these cases, feeding was problematic. Children either were fed by gastrostomy or might have physically benefited from the initiation of gastrostomy feeding. Parents' accounts and media reports positioned g-tube feeding as contributing to and part of a context of care that was unbearable for the entire family. Although these cases may not represent most families' perception of caregiving work, they do indicate that gastrostomy feeding has significance for families beyond its ability to correct undernutrition and minimize the risk of aspiration in their children. Gastrostomy feeding seems tied into the notion of disability itself.

These media reports made a strong personal impression on me. I was diagnosed with a chronic illness as an infant. Although the disease has been in remission for a number of years, I lived with a mobility impairment for most of my childhood and continue to live with a visual impairment. I have been involved in activism around the issue of disability, and I am strongly committed to the ideals of independence, integration, and accessibility. I believe that people with disabilities
should be enabled to participate in all aspects of social life, and that the removal of structural barriers, particularly economic is critical in realizing the ideals of the disability rights movement. However, I am also aware that many individuals with disabilities, including myself, are in a position where we are dependent on the goodwill and generosity of others. There have been many times when I recognized that this "goodwill and generosity" among my friends, colleagues and family has been threatened. In the absence of structural supports to provide opportunities for independence among people with disabilities, drawing on personal relationships becomes more important. I have often wondered how those relationships could be managed to preserve the dignity of the person needing help and to diminish the burden on the person providing the help. While I found the claim that unilaterally deciding to end the life of a person with a disability abhorrent, I was sympathetic with the situation of the parents in each of these incidents. Initially, I wondered if something could have changed in the feeding interaction between parent and child that would have either avoided the need for the initiation of g-tube feeding or would have made g-tube feeding more enjoyable for parent and child.

As part of a senior undergraduate thesis, I began observing feeding interactions between children with feeding impairments and their caregivers, whether a family member, staff person or volunteer. In the fall of 1995 I began to volunteer as a feeding assistant in the infant and toddler unit of a rehabilitation centre. During the following year, I visited the unit on Fridays from late afternoon until children were put in bed. This gave me the chance to observe children being fed their afternoon snack and dinner. Although I also participated in feeding children, their level of neurodevelopmental impairment was often so severe that most were g-tube fed and did not require assistance with oral feeding. As a result, I often participated in a number of other aspects of caregiving. Friday evenings were notoriously understaffed, since it was difficult to get volunteers to sign up for weekend evening
shifts and parents were often too tired to come in themselves by the end of the week. This meant I could find myself alone entertaining up to five children who were fed by gastrostomy.

I quickly learned that there was a tremendous gap between traditional nutrition research and literature regarding gastrostomy feeding in this population and its actual use. During mealtimes, children who used g-tubes might be found screaming in pain, or at the other extreme, might be found sitting alone for the duration of a ninety minute feeding. Children ripped tubes out of their stoma site. Other children vomited violently throughout their feeding. Children were almost always fed separately from the activities of others with less severe disabilities. The technology itself was fraught with difficulties, as tubes blocked, batteries ran out and pumps broke down. Often there were not enough staff or volunteers to adequately meet the needs (other than those which were physically threatening) of children while they were being fed. Rarely did g-tube feeding seem unproblematic; instead it appeared to be a deeply wounding experience for children. I was rapidly coming to understand why parents viewed gastrostomy feeding in such a negative manner. I no longer believed that something about gastrostomy feeding could be "fixed" so that parents would be happier with it. My instinct was that gastrostomy feeding as an intervention, needed to be reconsidered in light of the experiences of children like those I had witnessed.

I turned to theories around disabilities to consider how we might think about g-tube feeding differently. There is a growing belief, among both academics and activists in the area of disability, that an assessment of the environment in which individuals carry out their lives is necessary in order to fully understand how disability is either created or influenced (Zola, 1977; Oliver, 1992). While the biomedical definition of disability is exclusively focused on the functional impairment or physical pathology
(Hahn, 1997), a social constructionist and social creationist view broadens this definition by examining how the social, physical and built environments impinge on the activities and participation within the larger society of people who possess this functional impairment (Oliver, 1993a; Oliver, 1993b).

An expanded conceptualization of disability suggests that a complete understanding of the importance of gastrostomy feeding would include an exploration of its contextual issues. This complements the traditional medical focus on improvements in growth, the avoidance of aspiration and the avoidance of other physical side effects associated with gastrostomy feeding. Social interaction, physical setting, societal beliefs and attitudes regarding what should be eaten, institutional caregiving practices and even the feeding interaction itself are among the many possible components that comprise the context of children's mealtimes. Therefore the purpose of this study was to explore the context around gastrostomy feeding. Who feeds children when they have a gastrostomy tube? What are children fed? Where does feeding take place? Do children who are fed by gastrostomy have mealtimes? Why or why not? Ultimately it was proposed that a "picture" of the mealtime of these children would develop.

2.6 Framing the research question

In framing the research question and design, I have considered the work of Robert Murphy (1987), researchers in the sociology of childhood (Mayall, 1996) and Michael Oliver (1992; 1994).

2.6.1 Children's Voice

In his autobiography, The Body Silent, Murphy discussed how the disabled body becomes problematic in communication. Using interactionist theories, Murphy suggested that communication took place through verbal and non verbal means,
including gesture, proximity to others and body stance. In his own situation of encroaching paralysis, he felt that his ability to communicate was increasingly curtailed. Murphy argued that his disability progressively made him "silent".

The body of a child with a disability can be similarly silenced. First, because of their physical impairments, these children's bodies are limited in their capacity to take part in culturally signifying acts and interactions. Because of this, these children may be unable to communicate culturally in the same manner as the able-bodied population. Ethnography allows us to observe how children create their own ways to communicate. Similarly it may reveal the process of their being silenced. As well, many of these children are unable to speak verbally. Generally, an oral motor impairment affects speech as well as eating ability, given that similar motor control is required for the two skills (Arvedson et al, 1991). For purely pragmatic reasons, observational data seems to be the most effective means of giving children a greater opportunity to be informants about their own lives.

A second way in which children are silent is that their voices are absent from the discussions that concern their lives. A number of authors from the sociology of childhood have critiqued this absence and struggled to give children voice through advocacy and through including children in research (e.g. Mayall, 1996; Alanen, 1992; Blitzer, 1991). In spite of this, it has been very difficult to include the experience of children who have disabilities (James, 1994). Traditionally children have not been viewed as good informants, presumably restricted by their developing cognitive capacity and language skills and limited life experience. As a result children's concerns, as articulated from their own standpoint, have not yet been identified. Children, unlike other muted groups in society, may be at a particular disadvantage because they are not able to "organize" and compile their concerns (Oakley, 1994). Even so, children do not represent a homogeneous group,
but may have multiple variations such as race, class and ability. Children with disabilities, may have difficulty having their concerns recognized at first because of their social location as determined by their young age. Disability further distances children's experience from the generally accepted, taken for granted concerns associated with childhood.

2.6.2 Children and deinstitutionalization
The silencing of children is compounded by the fact that deinstitutionalization of children with serious disabilities, like those in this study, began only in the 1970's and therefore is a relatively recent phenomenon (Stoneman & Brody, 1984; Oliver, 1992; CILT, 1995). As a result, there is little empirical information guiding research agendas or policy with these children (CILT, 1995; Morris, 1994; Stoneman & Brody, 1984). Yet deinstitutionalization and community integration must place demands on children and families which need articulation.

Segregation of people with disabilities in residential institutions became more common with the advent of industrialization and the rise of capitalism (Oliver, 1992; Finkelstein, 1993) and persisted throughout much of the twentieth century. Families, particularly those who were poor, found it increasingly difficult to balance care for relatives with disabilities in the home with increasing work responsibilities (Oliver, 1992; 1993a). Residential institutions were purported to be a safe place to house people with disabilities (in addition to elderly people, people with mental illness; people with addictions etc.), allowing family members to be fully productive members of the capitalist enterprise.

A countermovement began with the publication of Goffman's (1961) work on institutional life, Asylums. His critique of the "total institution", in conjunction with several inquiries on allegations of abuse occurring within residential settings
(Schwartz, 1992), sparked a wave of anti-institutional sentiment among disability advocates. As the move back into the community got underway, a number of "new" problems emerged. Although they cannot be discussed here, one problem has particular relevance in this study. As Oliver (1992) has pointed out, deinstitutionalization has taken place in the same economic, political and social environment in which institutionalization was engendered. Presumably families will still have difficulty in balancing their public and private responsibilities. One implication of this is that many families may have tremendous difficulties meeting these twin responsibilities and that individuals with disabilities would continue living in "punitive" environments, or environments which shared many of the problems of the "total institution" (Morris, 1994; Oliver, 1992). There is a gap in our knowledge about how children and families have dealt with the move back to the community.

While on one hand this offers opportunities in terms of research, especially research that includes the perspective of children, it also means that current policy and practice may not reflect the needs and concerns of children and their families. In fact it has been argued that research, policy and practice regarding people with disabilities has emerged from an ideological stance which fails to consider the perspective of those living with disabilities (Swain et al., 1994). It is this contention made by the activist Michael Oliver which has provided the second major influence to my study design.

2.6.3 Defining disability

Oliver (1993b) has outlined several major criticisms directed toward research conducted in the area of disability. These include Finkelstein's (1980) argument that all approaches to disability to this point have focused on the impairment of the individuals as the ultimate cause of the disability, or stated somewhat differently,
the problems and concerns faced by people with disabilities arise from their physiologic impairments. The second major criticism is that research has failed to involve disabled people except as passive subjects. This means that research on disability has been based on models that are divorced from the everyday experience of people living with those disabilities. Oliver claims that much of the focus on disability research has been to "count" how many disabled people there are. This counting exercise has been performed to form a registry of disabled people or provide a database to plan and organize services. This exercise offers a number of benefits; for example we have not documented the number of children in Canada who are dependent upon technology nor have we attempted to amass any demographic data about them (DHC, 1997). However when "counting" is used as a complete approach, it often can arise from and contribute to the individualization of disability. If we consider that disability arises from social causes, we must recognize that the number of people with disabilities changes with changes to the social organization. Numbers also change with the definition that is used to measure disability. Oliver argues that for epistemological reasons, accurate data on the measurement of disability can never be produced.

Oliver (1992; 1993b) claims throughout much of his work that there are three major definitions of disability, each of which has taken a slightly different approach to accounting for the cause or origin of disability. These include the personal tragedy definition, disability as socially constructed or the interpretive approach and finally, the social creation approach. The first approach views the individual's disability arising solely from his or her physiologic impairment. Closely tied to the individualism and reductionism of the biomedical model, this definition of disability seeks to resolve individual problems through decontextualized acts of intervention; in the case of disability this often implies either acts of charity or medical intervention. The social constructionist view seeks a broader origin of
disability. It suggests that it is personal and social meanings which contribute to individuals being excluded from mainstream society. This definition implies that ending discrimination, changing attitudes and altering the social meanings of impairment and disability will alleviate the barriers disabled individuals face. Finally the social creation approach locates the origin of disability even more widely. This approach places the origin or cause of disability in the environment rather than within individuals; therefore the salience of a specific impairment is in part due to the situation the individual finds him or herself in. Oliver clearly feels that it is this final, social creation approach, that is the most relevant and appropriate epistemological and methodological approach to studying disability. Disability is not merely individual pathology or tragedy, or an attitudinal problem, but is a problem that is created by the institutions, organizations and processes that constitute the whole of society. Oliver urges that in disability research we ask what is being measured and counted. Is it heads? Is it individual needs? Is it the context in which disabled individuals find themselves and an analysis of the barriers and opportunities these environments provide? It is this last question that this study begins to examine through an ethnographic approach which provides the greatest opportunity to explore the daily context of the lives of children with disabilities and their mealtimes specifically.
3. DESIGN AND METHOD

3.1 Theoretical orientation
I came to this thesis as a nutritionist with an interest in social theory. I consider the origin of my theoretical orientation to be situated in biomedicine and to some extent, nutritional anthropology. My intent in this study was to conduct a critical ethnography, using relevant social theory as an analytic tool to interpret the data, uncovering the "story behind the story" (Van Maanen, 1989). I sought to move beyond a description of children's mealtimes, to explanations of why they looked the way they did.

3.2 An ethnography
Ethnography has its roots in anthropology, where the researcher observes, engages in and records the daily activities of individuals within a specific setting (Van Mannen, 1989). As Spradley (1978) describes, ethnography is "culture studying culture". The ethnographer carries in a knowledge base comprised of research methods, ethnographic theory and cultural descriptions and applies them to develop an understanding of a setting presumably from the perspective of those who live it. Ultimately ethnography is "... a written representation of a social setting or aspect of a social setting" (Van Maanen, 1988: 10).

Thomas (1993) refines this definition by making a distinction between conventional and critical ethnography, bringing it in line with Oliver's vision of research for people with disabilities. Conventional ethnography maintains a tradition of cultural description and analysis that "displays meanings by interpreting meanings". Critical ethnography involves a deeper, more reflexive research process, which pays attention to the structural forces which have a role in social setting. It demands a choice between conceptual alternatives, making value-explicit judgments of the
meaning and method throughout the ethnographic process. In turn this challenges
the research policy and practice. As Thomas suggests, conventional ethnography
tells us "what is", while a critical approach tells us "what could be" and what is in
need of change. To Thomas, critical ethnography takes conventional ethnography
and infuses it with a political purpose; transforming it to research that is performed
for the participants rather than about them.

Oliver's social creation definition of disability seems to call for this more critical
approach to ethnographic study. Like Giddens theory of structuration, there is
within Oliver's definition an implicit integration of structure and agency. Giddens
contends that people's actions may be in some ways dictated or constrained by the
structure of society. In carrying out the expected actions, individuals contribute to
the reproduction of the structure. However the term "re-production" acknowledges
the individual's ability to produce, thereby creating the potential to begin a change
in the structure based on his or her interpretation of the structure (Hale, 1990).
Individual meaning and social structures recursively influence and co-create one
another. Oliver might argue that as a society we have a shared understanding of
what constitutes "humanness", for example the ability to eat food, to speak, to act
independently (Taylor & Bogdan, 1989). Through a series of steps, this attitude may
become institutionalized, implicit in policies and practice. For example, one practice
observed in several schools and the rehabilitation centre, involved feeding children
who had g-tubes separately from those who could eat by mouth. There were a
number of possible explanations for this practice, however the result was that
children were isolated physically and socially from their more able bodied peers.
There was no explicit recognition that these children may have needed or wanted to
be included in the mealtime activities of other children. Without that recognition,
children were not only excluded, but no understanding of what might have been
gained (or lost) through the process of inclusion was ever developed.
In our research, we do not merely describe how children are fed differently, we attempt to expose why the difference has occurred and what the implications of this difference are. Therefore, taking a critical stance to ethnographic research, not only allows us to describe what happens in the research setting, but also to acknowledge that "what really exists" is not always accessible through observation of appearances. Instead we attempt to develop explanations for the underlying structures that influence the events and interactions within the research setting, at both their subjective and objective level (Poland, 1996).

3.3 The role of the researcher
The researcher is the primary research instrument in qualitative research. This presents a challenge in the research process throughout an ethnographic study. The researcher must gain access to the research setting, find a role within the setting ranging from complete participant to complete observer (Becker and Geer, 1957), and she must minimize the impact she makes on the research setting (Mays and Pope, 1995(a)).

One of the assumptions of participant observation, one of the methods of data collection in ethnography, is that the researcher shares in the participant's world (Denzin, 1989). Researchers endeavour to walk with the participants through their experience, directly participating in their symbolic world. This entails learning their language, their rules of etiquette, their eating habits and other daily patterns. One of the major risks facing the researcher is "going native" or over identifying with the culture at hand. Denzin (1989) suggests that one could counter this by keeping daily field notes on one's perceptions. Another suggestion is that the researcher create and maintain an identity for the research setting, with the understanding that observers tend to need a role in the culture that they are observing. Denzin
recommends that researchers not try to be anything that they are not: be an observer, a student or a researcher.

While Denzin's suggestions are helpful, there are some challenges facing researchers when working with children which need to be addressed. Typically researchers in the field try to de-emphasize their social distance from those who normally would be in the setting. However, Fine and Sandstrom (1988) have argued that this is not possible with children, since authority has a much stronger impact on them due to their "age, cognitive development, physical maturity and acquisition of social responsibility" (14). In every research situation, regardless of the age of the participants, it could be argued that researchers will always have difficulty "muting" their status. The role as researcher is to listen and watch, while the participants find their actions open to scrutiny. As well the researcher has the final power in representing what the individual reveals. Recognizing that children's status as "lesser citizens" only exacerbates this asymmetrical power difference they have with researchers, Solberg (1996) and Mandell (1988) have suggested strategies for how researchers could "be" in the research setting.

Solberg argues that researchers are at risk of stepping out of the role of researcher into the role of adult when working with children. One of the challenges facing the researcher is overcoming one's "adultist" stance (Waksler, 1986; Fine and Sandstrom, 1988; Oakley, 1994). The structures which shape our relationships with children are so pervasive it may be difficult to avoid slipping into the role of "parent" or "educator", the major structural relationships we have with children (Solberg, 1996; Mayall, 1996). Children may be equally influenced by the structures; therefore together we may interact in a manner which influences the research data in a way that reflects their situation as having less power. We may reproduce a particular adult-child interaction, potentially distorting children's voices. This
suggests that the observational methods which are part of developing an ethnography may avoid reproducing this structural relationship as opposed to an interview situation. As well, Solberg, like Denzin (1989) suggests that we focus more on what we are doing as researchers, than on who we are.

Mandell's (1988) conceptualization of the least adult role when working with children offers a framework of how this can be done. In her work examining young children's interactions in daycare centres, Mandell took on a role where she engaged in all the same activities as the children. This role was labeled "least-adult" because she consciously avoided all activities that adults would normally carry out in the daycare, such as discipline, assistance, mediating disputes or even getting objects from high places. Mandell was always clear about her role, stating that she was a researcher interested in what children do and say together. She never engaged in any caregiving activities, opting instead to sit in sandbox or play tea with the children.

Although I did not intend to carry out the "least-adult" role with the same tenacity as Mandell, I had wanted to refrain from any caregiving activities, leaving them to people who normally carry them out. I also intended and did, within reason, carry out many of the same activities as the children I observed. At minimum, I sat with the children throughout their activities. I did not share Mandell's confidence that this ensured a better rapport with the children, however I did impress upon all those in the research setting that I had a role that was distinct from other adults in the environment. As well, strictly defining my role ensured that I could stay with the child and observe the setting without having to pay attention to tasks I may have been asked to perform. In order that everyone understood my role and that they were informed about being observed, I told every person with whom the children interacted, that I was conducting a study about the daily lives of children
who have a gastrostomy tube. In spite of all of this, I found it impossible, particularly when I was with parents, to maintain this role consistently. The caregiving needs of children were so great, and the adults often so overburdened, that I was uncomfortable doing nothing. As a result, there were many times when I did perform caregiving activities with the children, such as reading stories, changing diapers, comforting a child when upset or feeding them. I believe the immediate practical needs that arose outweighed any bias that my activities would produce in the data.

3.4 Sample selection
Sample selection is based on the goal of obtaining an in-depth understanding of circumstances pertaining to the research question (Thomas, 1993). In qualitative research, sampling tends to be purposive. The idea is not to choose a sample that will produce information that can be generalized to the whole population. Rather, sampling is designed to produce data that will produce links, categories or themes shared between the setting observed and others like it (Bogdan & Taylor, 1978; Mays and Pope, 1995b).

Sample selection reflected the two strategies consistent with the ethnographic design of this study: observations and interviews. The sample from which the general observational data were collected was the group of people I encountered during my weekly visits to the rehabilitation centre. This group was heterogeneous, including children who used the rehabilitation centre, children's parents, siblings and other relatives, the centre staff, feeding clinic staff, children's private caregivers and volunteers. In general, everyone who was encountered in this part of the study, had a physical, cognitive and emotional disability, or was intimately involved in the care of a child or children with one or more of these impairments.
Interview and focused mealtime observational data from individual children and their families were collected from eight purposively sampled families. Participating families were recruited through the feeding assessment clinic at the rehabilitation centre. Letters of recruitment were sent, by the feeding clinic physician, to 22 families whose children met the study criteria. Initially, letters were sent prior to a family's visit to the clinic; however this strategy was abandoned due to the low numbers of eligible participants who visited the clinic during the recruitment period. Patient lists for the past year were examined for eligible participants. Seventeen families responded to the invitation, although not all were able to participate. In two families children had regained oral feeding skills and were no longer using a g-tube. In another three, children were too medically fragile to participate in the study, in that they were recovering from surgery or had pneumonia. In one case, the child was in a group home and the family was unwilling to have me visit their child in that setting. Mothers in the remaining three families agreed to participate in the study, but later withdrew their agreement when their husbands did not want to participate. Finally eight families agreed to participate. Once families agreed to participate in the study, I met with them to discuss the study in more detail, decide how meal and feeding time observations would take place and go through the informed consent process.

Eligibility criteria for this study included screening for families with children who had a gastrostomy tube in place for at least six months. It has been suggested that for most families, a gastrostomy tube is viewed as a temporary intervention initially; however once three to six months have passed, families tend to view the feeding method in terms of long-term management (Guerriere, 1998; Brotherson et al, 1995). As well, this allowed more time for children to recover from the physiologic conditions which may have precipitated the insertion of the gastrostomy tube, such as severe undernutrition or chronic lung infections. All children in participating
families were fed primarily via gastrostomy, so that there was an opportunity to see feeding in progress.

The children who participated in the study have been given the pseudonyms Sam, Rayna, Joshua, Tim Jr., Star, Lindsay, Wilson and Gary. Informal interview data were collected from Lindsay and Joshua, who had verbal communication skills. Formal interview data were collected from each child's mother, two children's fathers and one paid caregiver.

Because of the nature of observations with the eight participating children, a third sample of participants emerged. This sample was comprised of various groups of individuals, such as teachers, classmates, nurses, health care aides, housekeepers and clinicians with whom the children came in contact during the course of my observations with them. The precise number and demographic characteristics of this group are not known. This form of data collection was aimed at developing a sense of context in which the children carried out their daily activities. While some individuals were met repeatedly through the course of this study, in general observations and conversations with these two groups was much less formal than those with the eight children and their families. Data from these participants is integrated into the analysis and discussion which follows, and is often identified by the setting in which they were gathered. For example, there are references to discussions of team members and visiting families which occurred in the feeding assessment clinic.

3.5 Data collection
As opposed to other research paradigms, the research design in an ethnography can be fairly loose and flexible in the beginning of the research process (Thomas, 1993, Schatzman and Strauss, 1988; Charmaz, 1990). As the research is initiated and then
progresses, the specifics of the research design are developed. In this emergent design process, the researcher begins with a broad general question, either substantive or theoretical. The researcher asks participants general questions at first, becoming more focused as the research question narrows, and gaps or contradictions in responses are noted (Schatzman and Strauss, 1988; Charmaz, 1990). This initial loose structure potentially maximizes the discovery and grounding of theoretical interpretations (Denzin, 1989).

The primary method of data collection for this study is participant observation. Participant observation refers to a research method characterized by a period of intense social interaction between the researcher and the informants, in the milieus of the latter (Bogdan & Taylor, 1975). The researcher immerses him or herself into the research setting. Fundamentally field research involves watching and recording what people say and do. The researcher is the data collection instrument and will document the world she observes, systematically recording and analyzing her observations and possibly her reactions to them. As Becker and Geer (1957) contend, participant observation offers the unique opportunity to see talk and action together, offering a particular advantage over interviewing techniques. They suggest that people are sometimes unwilling or unable to talk about things the researcher might wish to know. It is not simply a matter of being resistant to the researcher's questions, but could be that they feel the information is unimportant to the interviewer or the information is so taken for granted, that the interviewee is not "conscious" of the information (DeVault, 1991).

The data that are presented in this study were gathered primarily from interviews and meal and feeding time observations with children with severe neurodevelopmental disabilities in their home or school setting. Data from participant observations at a children's rehabilitation centre and a feeding
assessment clinic, settings where mealtime observations and parent interviews sometimes took place, are also integrated. The data collected from the eight children and their families were collected from August 1997 to March 1998.

3.5.1 Observations

After each session of observation, I recorded my observations, experiences and reactions in field notes. In recording data, the researcher attempts to develop a thick description of the research setting (Denzin, 1989). Thick description strives to capture the meanings, actions and feelings that are present in an interaction experience. In another sense, thick description is also interpretive in that it attempts to illuminate the meanings persons bring to their experiences. Participant observation may be particularly suited to the development of this form of "interpretive" thick description, since the meaning of words and actions can be learned from observing their use in context (Becker & Geer, 1957). It attempts to show how these meanings unfold during the interactions (Denzin, 1989).

In total, there were fifteen mealtime observations with children. Gary and Star were each observed once during a lunch in a public mall. Lindsay was observed during three meals, one late breakfast in a cafeteria and two lunches in her school. At the time of her participation in the study, Lindsay was living in a long-term care facility, which included her school. In a sense, the school was her home environment during the course of the study. Joshua was observed throughout three separate lunches. The setting for one lunch, was an institutional cafeteria, and the two others took place at his home. Sam was also observed during three lunches, one in his home, one at his school and one in an institutional cafeteria. Tim Jr., Rayna and Wilson were observed through two meals, one in their home and one in their school. Several of these children attended the same schools and therapy clinics,
therefore it was not unusual for me to see the same children in one another's mealtime environments.

The observations in the feeding clinic and the unit in the rehabilitation center were instructive on several levels. First, they familiarized me with the language and "culture" peculiar to caring for children who are dependent on technology. In these settings I was exposed to a range of activities essential in caring for children and their technology such as suctioning, personal hygiene routines and ad hoc equipment repair. Although a number of crises arose during my observations with the eight children in this study, observations in the feeding clinic and rehabilitation centre afforded the opportunity to observe a much wider range of problems first hand. Observations in these settings also exposed me to children at different stages of experience with feeding impairments and use of gastrostomy tubes. This could range from families grappling with the decision of placing a g-tube in their child to the anxiety of a young man at the prospect of having his g-tube removed after eleven years of relying on it to supplement oral feeding. I gained a sense of how families were engaged in an ongoing process of learning how to "cope" with the g-tube. Issues around feeding one's child via g-tube were continually evolving. Some issues resolved as parents gained experience with the gastrostomy or found new ways to negotiate mealtimes in their family. Other issues arose as children changed schools, became ill or had physical setbacks or improvements. Another advantage to obtaining data from different stages of children's lives and level of experience with g-tubes, was that the data could act as a form of triangulation. Parents' descriptions of their reactions to the first suggestion that their child should have a g-tube inserted or their descriptions of events that typically occurred in the schools or rehabilitation centre closely matched my observations. The alignment between families' accounts, mealtime observational data and findings from other researchers contributes to the validity of the data collected in this study. Another aspect of
noting similar patterns in children's and families' experience were also helpful when identifying potential areas for exploration and analysis. For example, observations of parents' anxiety at placing their child in respite care dovetailed with pejorative comments of interviewed families regarding institutionalized care. This intersection of data was useful in initial coding and categorization of data, and later contributed to an integral portion of the final conceptual framework of the study. Opportunities for analysis were also identified in places where there appeared to be a disjuncture between interview and observational data. The two most striking illustrations of this were parents' perceptions regarding various feeding strategies and their children's reaction to the strategies; and the vast difference between the level of progress families felt their children could achieve and that which feeding assessment team members repeatedly stated was realistic.

3.5.2 Interviews
In keeping with the emergent design process, my initial focus was broad. The original design involved tracking the activities of children through their daily activities. I was to accompany children throughout parts of a typical day's routine on three separate occasions. I intended to act as a participant observer, observing children 's activities, behaviours and interactions and conversations of others in the research setting when the data seemed directly related to the children I was studying. I was particularly interested in any data related to feeding, meal and snack times and maintenance of the gastrostomy.

This research design was introduced to families in the recruitment letter and then explained again during the informed consent process. It was in this second conversation that parents expressed their desire to be interviewed. Most families expressed confusion and skepticism at my suggestion that I wanted to observe their child through a meal or feeding time. Most reframed my request as one of wanting
information about their child’s use of a g-tube. Although I never asked to conduct formal interviews with them, all parents "agreed" to be interviewed by me. Given parents’ comments during the initial conversations, the informed consent process and their actual interviews, there seemed to be two purposes behind this reframing of my request. First, the interview may have served as means of learning more about me before they introduced me to their child. I certainly perceived the interview as critical in establishing rapport with the family and gaining entry to the field. As well, parents stated that they had an important story to tell and important information to share. All parents asserted that there should be a partnership between hospitals and parents in caring for their children. While parents did not always express confidence in the knowledge that doctors possessed regarding their children's well-being, they unanimously believed that parents' knowledge was essential in understanding the needs around gastrostomy feeding. "We have a lot of important information" was commonly heard from parents with respect to caregiving of children with gastrostomy tubes. Parents all hoped their stories would be helpful to other parents in similar situations.

Two types of interviews occurred with parents. All parents took part in an audio-taped "formal interview" that ranged from one to two hours in length. Parents also took part in less formal interviews, usually as part of preparing or de-briefing around observations with their children. Often parents had "saved up" information that they remembered since our last meeting or conversation. Interviews were conducted at a location of the parent's choosing, in either their home or at the rehabilitation centre. All families, with two exceptions, initially met me at the centre, either in the feeding clinic or for the first interview.

The interview format followed that described by Kvale (1996) and Silverman (1995). The interviews were open-ended, and were audio-taped with families' knowledge
and consent. Each person being interviewed was told that the purpose of the
interview was to learn more about meal and feeding times of children who were fed
with gastrostomy tube. Each participating parent was asked some general questions,
but the direction of conversation depended on the interests of the person(s) being
interviewed. The role of the researcher in this part of the study was to encourage
each participant to discuss areas she or he felt were important and ask probing
questions to either clarify or further explore a specific issue. Later in the study, I also
asked questions that related to previous data and the emerging analysis.

The general questions, asked of each family, ensured that certain topics were
covered. Interviews were opened by asking families to tell me about their child's
use of a g-tube, particularly how they had arrived at their current situation.
Interviews were begun this way in part as a response to a clear desire by parents to
"tell their story". This was evident as I began to integrate the formal interview
component into the study design. Families were also asked to describe their
mealtimes, to discuss food-related events such as holidays or birthdays with their
child, to discuss their level of support and available resources around mealtimes,
and to describe challenges and opportunities related to feeding their child by g-tube.
The timing and order of the questions varied to fit with the flow of the
conversation. On a number of occasions, the person being interviewed raised the
topic on her or his own. In these instances, I would let the person know I had
intended to ask the question, and that it was a concern shared by other parents.

As mentioned earlier, interviews were held in locations convenient to the parent.
Sam's mother, Ruth, was interviewed twice, once in her home and once at the
rehabilitation centre while Sam was at a dental appointment. Melissa was
interviewed twice at the rehabilitation centre while her son Joshua was at a therapy
session, and once in her home while Joshua played in the next room. Mary was
interviewed once at the rehabilitation centre over lunch with Lindsay. Patricia and Tim Sr. were interviewed in their home once while their son Tim Jr. was at school. Cassandra, Star's mother, spoke to me frequently over the telephone, and was formally interviewed in her home once while Star was at school. Roberta, Gary's mother, was interviewed in her home while Gary napped. Rayna's parents, Steve and Adriana, were interviewed in their home with their two children present, in addition to speaking to me extensively over the telephone. These conversations were particularly interesting because the telephone was put on speaker and the entire family participated in the conversation. Finally, Carolyn was interviewed at the rehabilitation centre while her son Wilson was at a therapy session. All interviews at the rehabilitation centre took place in the cafeteria. Mothers were offered the chance to be interviewed privately in one of the feeding clinic rooms, but all refused. Their responses were similar in that they thought the cafeteria was a beautiful room and that they would be able to get something to eat. This reaction may indicate the limitations in mothers' lives, in that they had to combine different personal activities in order to get everything accomplished. It may have also reflected their need to relax in a place that, at the time of the interview, was both attractive and frequented by other adults. The offer to interview parents in one of the examining rooms may have been inappropriate, given its clinical atmosphere and the large amount of time families spent in these sterile environments.

In the interview with Roberta, Gary's health care aide, Jan, was present and participated extensively. Jan's comments were transcribed and included in the results and analysis. Roberta referred to Jan as a member of the family on several occasions, both throughout the interview and once in a telephone conversation. While Jan appeared to have an intimate caregiving relationship with Gary and Roberta, it is possible that her presence influenced Roberta's interview data. Instances where Roberta provided different information or reactions in private
conversations from that given in the interview with Jan are noted in the results and subsequent discussion. The presence of children themselves did not appear to affect families' remarks. The content and tone of remarks made by families during the interviews and other conversations were consistent. Even highly emotional comments, such as anger directed towards physicians or sorrow over seeing their child's "suffering", were shared, regardless of children's presence.

3.6 Data analysis
In data analysis, the researcher's task is to sift and decode the data to make sense of the situation, events and interactions (Mays and Pope, 1995). In essence, the analysis of observational data involves isolating a strand of the experience made visible to the researcher and developing it into the beginnings of a theory or typology. Interpretation of the data is used by the researcher to build a cognitive and/or emotional understanding of the other's experience. It is a clarification of the meanings embodied in the speech and behaviours of those who are studied (Denzin, 1989).

In order to isolate the meanings and major themes within the data several strategies can be used. Generally, field research lends itself to thematic analysis. Some kinds of experience, sentiments and beliefs may remain inexpressible in the scientific format of direct questions, yet they may be evident in the data through critical thematic analysis (Luborsky, 1994). Conversely, themes can be used by individuals to provide structure and coherence, and even explicit points of meaning to their interactions. Themes are often linked with western values of holism, understanding, and completion. Themes, which become evident in the data, tend to be culturally laden, built within our sociocultural norms. As Luborsky (1994) suggests, when a theme appears within collected data it may be evidence of explicitly important personal or sociocultural meanings to the informant. However the
theme could also have been produced situationally as part of a strategy for presenting a credible, coherent, and successful account or interaction. As well, they could be an artifact of the analyses without meaning to the informant, but meaningful to only the researcher or reader. Often however, themes which are evident in the data are indicative of each situation.

Critical theory expands on this last point. Kinchloe and McLaren (1995) suggest that the way we analyze and interpret empirical data is conditioned by the way it is theoretically framed and is dependent upon the researcher's own ideological assumptions. This alerts us to the fact that empirical data cannot always be treated as truth. The theoretical and ideological assumptions I brought to this data are outlined above in my framing of the question.

With this in mind, the analysis of the collected data occurred in an iterative process. Analysis took place on two fronts. First, observational data recorded in field notes were compiled and summarized. Particular attention was paid to data which were related to mealtimes, feeding, gastrostomy tubes and children's feeding impairments. While the observational data collection and summaries were conducted, literature on disability theory was used to develop a sense of possible themes present in the data. The bulk of the analysis was focused on the interview data. This analysis occurred in several stages: summary, descriptive coding, conceptual coding and development of an initial conceptual framework. Data collected around each child was collapsed into a "story". The content of the story was derived from data collected both through interviews with parents and observations of children. This was done to provide a sense of context for each child and retain the integrity of their experience in light of the "deconstruction" that typically occurs with qualitative analysis. It provided a counterpoint when I was developing a more theoretical analysis; I could compare my developing analysis
against individual stories to see if the analysis "made sense". The development of narrative for each child also proved useful in comparing the impact of structural forces on families' lives. Chapter 5 demonstrates how stories are used to develop a case comparison analysis of families' work to negotiate social assistance systems.

The second stage of the analysis was based on the methods outlined by Charmaz (1993). It involved returning to the original interview transcripts and coding them descriptively. Some of the data were then sorted according to five recurring themes: food, feeding, formula, gastrostomy tube and mealtimes. Within each descriptive category, data were re-coded using another layer of descriptive and now conceptual themes. Data were re-categorized according to emerging theoretical/conceptual themes. The emerging theoretical understanding from the data was written in the form of a second narrative, in order to develop a conceptual understanding of the context in which children were fed. This narrative differs from the one described earlier, in that it integrates the experiences of more than one child. At this stage, insights gained from the observational data were integrated into the narrative, along with related theoretical constructs from relevant literature. This writing process helped refine the interpretation of the data, indicating opportunities for further analysis or potential research. As gaps in the narrative appeared, I would return to the data, coding once again, each time at a more conceptual level. Each interview was analyzed in this manner successively as the interview was conducted and transcribed.

The major conceptual focus that emerged from this data was the centrality of normalcy discourse in the lives of families with disabled children. Parents continually grappled with the fact that their child, and consequently the whole family fit few norms. Two major conceptual themes were developed separately but simultaneously from the data during analysis. The first related to "working the
system". This captured efforts by parents to try to get their child's feeding impairment (in addition to a range of other needs which arose from their primary diagnosis) accommodated within the community. The second set of concepts related to parents' strategies to feed their children. Both sets of themes are ultimately related to families' attempts at "normalizing" their children in spite of the severity of their disabilities. The relationship between these two sets of themes is hypothesized in discussion and conclusion.

3.7 Definition of context
Since this thesis is concerned with illuminating the context of children's feeding experience, it may be helpful to develop a definition of context. For this study I have chosen to use the definition by Conrad (1990). He describes context as involving both static aspects of environment and the processual nature of people's settings. Context can be a process, since our personal and social meanings which help us define our context change over time. Stoneman and Brody (1984) state that context may be a physical setting, the presence or absence of different persons, or a combination of settings and persons. For example, families can be viewed as both living within a context, as well as contributing to the creation of new contexts through their thoughts and actions. Therefore, the study of the context of feeding may include an examination of who is involved in the interactions, the different physical milieus within the setting (such as toys, dining tables), the social milieu and the different activities or materials which occasion different interaction patterns. Finally, it may also include the prevailing discourses on the meaning of food, eating, disability, g-tubes and formula.

3.8. Overview of the children and their families
The eight children in this study ranged in age from 3 to 16 years. There were five boys and three girls in the group. All the children had some form of
neurodevelopmental impairment, and in six children this included a cognitive component, such that children had extremely limited to no verbal communication. Of the two children who were able to communicate verbally, one was quite articulate, while the other had difficulty speaking due to a recent cerebral vascular accident, related to her primary diagnosis. Spastic quadriplegic cerebral palsy was the most common diagnosis among these children. One child had acquired cerebral palsy as the result of asphyxiation during an asthma attack, while the rest had CP as the result of birth trauma. Of the three remaining children, two had impairments arising from inherited conditions. The third had a possible diagnosis of autism.

All the children who participated in this study had a gastrostomy tube, which had been inserted by age three. Sam, the 16 year old, had been using a g-tube for thirteen years, the longest in the group. The shortest duration was 6 months, although this child had used a g-tube for several years when she was younger. All the children had eaten by mouth for at least a one year period in their lives. However, with the exception of the one child who acquired cerebral palsy later in life, all the children had seriously impaired feeding prior to the g-tube insertion, with feeding characterized by aspiration, severe reflux and/or very poor eating efficiency. All the children were also seriously undernourished prior to the insertion of the g-tube.

For the most part, the children in this study had tightly regulated and full schedules. Only one child in this group, Joshua, did not attend school. His mother had been trying to enroll him in a private school, but had difficulty finding a school willing to risk the liability of having a technology dependent child. The other children in this study attended school at least for half a day. All the children including Joshua, attended a variety of day programs, or received special rehabilitation programming at home. From parents' descriptions of different outings and family occasions, as well as the difficulty I experienced in trying to find times that I could observe the
children, it seemed that the children in this study were involved in a fair number of social and medical activities. All activities were put on hold as soon as children became sick or experienced some type of medical crisis.

Six of the children lived in a large urban area, while two lived in rural communities. All children lived with their families. Only one child lived in a single family dwelling with his parents. The others lived in some type of apartment or townhouse complex. Of these, three children lived in subsidized housing. Although seven of the children had some form of mobility impairment and used wheelchairs, only one lived in "accessible" housing. However this subsidized "accessible" unit was so small that it was impossible for this teenager and his family to move around their home comfortably.

3.8.1 The families
Family composition in this study reflected the range of families in which children with disabilities live. An attempt was made to obtain demographic data about the study participants and their families, however it was evident immediately that they were uncomfortable about providing this type of information. After the first few efforts to ask families to complete a demographic information sheet, it was clear that families were concerned that the information could be used "against" them, particularly with respect to their eligibility for home care support. This concern is understandable when we consider the enormous difficulties some families endured before they received consistent government assisted support. It also appeared that some information was being created on the spot, as some families took no pains to conceal the fact that they were giving me false responses. Again, this behaviour can be better understood when we consider the lengths families will go to "work the system", as discussed in Chapter 5. Families often find themselves in an adversarial relationship with medical, school and social assistance systems and may have been
unwilling to offer any information that could have weakened their position. Another possibility is that these families often are required to disclose information about their personal lives. While families were willing and in fact eager to disclose some very intimate details of their lives, they may have been reluctant to give me the specific information which I was actively requesting. If we consider how families initially set their own agendas for the formal interview, it is conceivable that they wished to remain in control of the information they shared. Therefore, demographic information is primarily taken from volunteered information during the caregiver interviews.

Five children were in families headed by sole support mothers. Of the five mothers, four were receiving welfare. One of these mothers had quite recently begun receiving social assistance, following the dissolution of her relationship with her children's father. She believed that her situation would be temporary. Each of these four mothers however, had been employed and used language such as "well-off", "comfortable", "not rich, but never worried" to describe their economic situation prior to their child's disability, or when relevant, the dissolution of their relationship. Each had also once hoped that her situation would improve, however as time passed they seemed to accept that this may not occur. As Melissa noted:

I never imagined this was going to happen...Everything I have goes to Joshua, I get him programming, clothes, toys, books...I've even fund-raised the tuition to put him into a private school. We're also very lucky that we got this great apartment. But every now and again I stop and think, my god, I'm on welfare...we're poor. And I can't see the end anymore.

The fifth mother was unique in this group, in that she was an adoptive mother. She was in her mid fifties, and had adopted two children with disabilities after she had built up the resources to do so fairly comfortably. Although she was employed in a professional occupation, she had achieved enough status in her workplace to ensure a more flexible work schedule. This may have allowed her to accommodate
the many emergencies that arose with her children, with fewer consequences than one of the younger parents in the study might have experienced.

The remaining three children lived in two parent families, with a mother and father who were married. Like the group described above, one family stood out as unique. Both parents in this family were older, in their forties, and had their first child when they were established professionally, financially and within their relationship. This family clearly possessed more resources, financially and perhaps even personally, compared to other families within the study. Certainly they appeared to have the most secure material future. The other two families were the least willing to discuss their current financial situation, perhaps because of the difficulty both had experienced in trying to get consistent support from home care agencies at the time of the interviews. However both these families referred to difficult financial times when they relied on social assistance to "tide them over". In all three families both parents worked, and in each it was seen as necessary both financially and in terms of the mother's well-being. All three of these families discussed how the pressure of dealing with their child's disability, particularly the feeding impairment, put enormous strain on their marriage. This is of particular concern when we note that the two youngest couples had the youngest children in the study. They were aware of how vulnerable their marriage was and they recognized that health professionals, families and friends did not expect their marriage to last. In spite of this they were determined to continue trying to stay together.

3.8.2 Caregiver support
A constellation of individuals provided primary care to the children in this study. For the purpose of this study, caregiver will refer to any individual, other than a parent, who provided care to a child. Five of the children in the study had siblings,
some of whom were involved in feeding the children, as well as contributing to other aspects of care. In one case, a grandmother had immigrated from the Caribbean to help her son and daughter-in-law care for their child. Some families talked about receiving both financial and practical support from extended family members, however this support did not seem to be perceived as consistent or adequate.

In several instances the caregiver participated in the family interviews, although with one exception, they tended to contribute minimally. They offered an occasional point of clarification or as often was the case, challenged the parent. It was clear from the parent's interviews, and in trying to find times to observe the children during mealtimes, that many individuals offering varying degrees of support, frequented each home.

3.9 Presentation of the Finding
The presentation of findings and their discussion will reflect the nature of data analysis. The findings and commentary about their significance are integrated in the next four chapters. Chapter Four, The Normalcy Imperative, introduces some theoretical work by Michel Foucault which served as an analytic lens through which families' experiences and practices were examined and interpreted. The chapter highlights some relevant concepts regarding governance and normalization, particularly as they apply to the task of raising children. The next chapter, The Marginalization of Families, covers the larger social context in which children with disabilities are raised. More specifically, the experience of families in trying to attend to societal expectations that their children be integrated into a community which provides little assistance in this endeavour will be explored. Chapters Six and Seven, look much more closely at children's mealtime context, outlining the different feeding practices parents use to construct children's mealtimes, the
mealtime constructions themselves and the symbolic and social implications of these constructions.
4. THE NORMALCY IMPERATIVE

Foucault's work on governmentality is useful in considering the imperative of normalcy which will be evident in the lives of the families in this study. His ideas provide insight into understanding why families wish to subdue difference in their children and why mealtimes become one place in which to do this. Foucault's work helps us see the link between families' interactions with institutions and the strategies they use to construct their children's mealtimes.

4.1 Governance

Foucault suggested that society is ultimately concerned with the economy, defined as the management of individuals, goods and wealth (Foucault, 1991). Historically, societies were concerned with the protection of property, given that wealth was derived from land holdings and the resources which they could offer. As wealth could be achieved through a productive labour force, that is through industries, governments became concerned with the protection of individuals and the population to ensure their security in terms of wealth, resources, health and happiness (Nettleton, 1997; Foucault, 1991).

In his overview of Foucault's work, Rabinow (1984) suggests that there are two means by which societies are able to achieve this management. These are individualization techniques and totalization procedures. Society's power rests in its ability to both individualize and totalize its population.

Individualizing techniques strive to objectify the subject/individual. They employ three strategies which highlight salient characteristics of the individual and then essentialize the individual based on these characteristics. As a result, the complexity
of the person is reduced and the potential influences of the context in which people live are ignored. The first strategy involves "dividing practices". Individuals are divided from others, and then replicate this marginalization within themselves. As a result dividing practices give individuals both a social and personal identity. The practices use science/rationality to effect exclusion of the individual, sometimes spatially, always socially from the main group. McKnight's (1995) discussion of the segregation of people with developmental disabilities illustrates how this can occur. Based on intellectual or cognitive impairments, groups of people were removed from mainstream society and placed in institutions which were often outside the community both in terms of physical location and social functioning. In turn, individuals learned that there are behaviours or characteristics which they possess which also must be distanced or kept hidden from others. Following McKnight's example, many people with cognitive or psychiatric impairments have a keen sense of their "odd" or socially inappropriate behaviours or characteristics which must be controlled and not allowed to surface in public (Schwartz, 1992).

The second means by which to objectify the individual is "scientific classification". Unlike dividing practices, classification is not concerned with the domination of marginal groups, but rather as the term suggests, it helps create an identity based on presumably neutral characteristics. For example, identity is created for an individual by the medical system through "objective" diagnoses. Therefore the diagnosis of an oral motor impairment among the group of children in this study contributes to their identity as persons who have severe disabilities. The final strategy is termed subjectification. While the two techniques described above are imposed by external sources upon the passive individual, this technique is also self-imposed and self-forming. It involves a process of self-discovery or self-understanding, although usually in relation to an external authority figure.
These individualizing strategies are evident in the lives of the families in this study. The need to be fed via gastrostomy and the disability in general, serve as salient and essentializing characteristics about the children and to some extent the family. In a sense, families of children with a gastrostomy experience a form of "courtesy stigma" (Goffman, 1961: 29-31). Goffman contends that courtesy stigma is held by subgroups of the "wise" who are associated with the person who bears the primary stigma. Courtesy stigma refers to the discrediatable stigma conferred upon intimates of the stigmatized. Families of individuals with disabilities, all share in the social distance and discredit of their children's stigma. Parents' recognition that the insertion of a g-tube placed their child into a new category of disability, suggests that the technology becomes indicative of the way children, and eventually the whole family, are "divided" from their peers. This strategy is also carried out in the school system where children are fed separately from their orally fed classmates or when they are refused admission to a school because of their use of a g-tube. Dividing practices were also evident in the medical system, when parents were refused some services because of the specialized nature of their children's needs. The basis of this exclusion lies in part in the supposedly neutral classification of technology dependent individuals as "severely disabled" (WHO, 1980; DHC, 1997). This classification apparently entitles children and their families access to more support services. Unfortunately the classification also marks children as exceptional, or "special", which in practice limits their access to other services, like the school system for normal children. The final strategy of subjectification is demonstrated through families' descriptions of themselves as different, as "dysfunctional" around their mealtimes. It may be this final self definition that renders families so vulnerable to what Foucault names totalizing procedures.

Totalization procedures, the other component in society's power, ignore the individual. Instead, they are concerned with the citizens of society; or more
accurately with a class or a group among citizens. The government uses both surveillance and normalization procedures to enact its totalizing powers on the population. It is the latter in which we are interested, although surveillance procedures are also used in the lives of these children and their families. Foucault understood normalization as based on a "system of finely gradated and measurable intervals in which individuals can be distributed around a norm" (Rabinow, 1984: 20). Increasingly, we have statistical measures to judge what is normal within a given population (Turner, 1992). Normalization technologies aid in the "systematic creation, classification and control of anomalies in the social body" (Rabinow, 1984: 21) to ensure the economic stability of the society. To accomplish this, technologies of normalization identify anomalies in the population and then try to normalize them.

A problem in this process is that measurement and classification create the very anomalies they seek to correct. Rose (1990) discusses this as one of the difficulties with using the normal distribution. In constructing the distribution, some individuals are inevitably at the extreme ends or tails of the curve. Therefore, as Rabinow points out, the ability of the society to create an "increasingly totalizing web of control" is linked with and dependent upon the simultaneous creation of an increasingly more detailed system of the characteristics of individuality. As individuals we are at once objectified on the basis of a variety of characteristics, while we strive to move our identity closer to a norm, held by the majority of the population. A powerful sense of what constitutes normalcy with respect to eating, childhood and/or family life, acts as a totalizing factor for the families in this study.

4.2 Self governance

As described above, activities of society related to control and governance, are predominantly those of collecting, collating and calculating data on the
characteristics of the population. Society collects this information to ensure that it is effective and capable of establishing a healthy, happy and productive population. These institutional activities are complemented by those of individuals who engage in practices of the self or self-government (Nettleton, 1997). Therefore society relies increasingly on technologies of the self. In this population, technologies of the self include keeping children as normal and as healthy as they can be; in specific terms, minimizing aspiration and infection and maximizing children's growth.

This "partnership" between the whole of society and its individual citizens means that "government does not just subject "its citizens" to policies and programs, but requires that they participate" (Nettleton, 1997; 212). In terms of their health, individuals are encouraged to take care of themselves. The means by which individuals are encouraged to do this eventually shape how they come to think of themselves (Nettleton, 1997). For example, individuals are encouraged to minimize their risk of cardiovascular disease by monitoring their diet and increasing their physical activity. Individuals may engage in these activities, however they come to think of themselves in relation to their risk of disease (Lupton, 1996).

Governance functions at the level of "political rhetoric, institutional practices and individual conscience" (Nettleton, 1997; 213). Political rhetoric publicly presents an ideal or norm for us to aspire towards, with respect to our health. There are a number of ways any health issue could be conceptualized, but governmental policies synthesize political rhetoric to develop a particular problematization of the issue at hand. As result, policies reduce the complexity of the issue and help delimit our actions in relation to it (Osborne, 1997). Therefore policy regulates what can and cannot be said or done about the issue. Policy also helps us identify the characteristics of issues or individuals affected by various issues, which must be measured and controlled. Policies outline institutional practices. These practices
are targeted at the characteristics to be normalized. Walkerdine (1984) illustrates this function of policy through her discussion of school policies. She suggests that even the most simple of "rules" or policies, such as having children form quiet lines before they can enter or leave their classroom, "tells" children that bodily movement is to be controlled. In the lunchroom, children are taught that food has to be eaten rapidly and tidily, there is no place for the child who vomits, chokes or is messy throughout his or her mealtime. Individual conscience is shaped by the norms expounded through political rhetoric. We then enact these norms, entrenching them further and reproducing them.

The political rhetoric that operates in the lives of the participants in this study is that of the importance of family-based long-term care. Although it is difficult to identify where families encounter this rhetoric, their comments regarding institutions indicate they have been exposed to it. In fact, their comments may serve as a means of perpetuating the discourse and transmitting it to other families. For their children to be normal they must participate or be integrated into the community because there is no "place" for exile. However, the rules of integration, evident in institutional policies and practices suggest that one must first be normal in particular ways to participate in the community. The ability to eat by mouth and to eat "real" food becomes the characteristic to be monitored and evaluated, in the effort to normalize one's child. At a broader level, the ability to control children's bodies, in essence their functional impairment, becomes a means by which the entire family becomes normalized.

Nettleton (1997) points out that recent discourses on health have integrated, demonstrated and contributed to the ideal of self governance. The act of governance is seen to be shared between society and the individual. The responsibility for caring for one's well-being, whether it be in terms of wealth,
education, resources or health is not only the responsibility of society as a whole, but also the responsibility of the individual. Therefore the individual moves from being a relatively "docile, passive recipient of advice and health care to one who possesses the capacity for self-control, responsibility, rationality and enterprise". Health has become a matter with public implication: it is our social duty to be healthy - we can no longer consider health a private matter (Lupton, 1997).

4.3 Self-governance and the family
As governance around health became shared between the individual and the society, there was a recognition that children's health also needed to be maintained (Lupton, 1997). Families, particularly mothers, were given the responsibility of monitoring the maintenance and development of children's bodies. Structures, such as the milk stations in Australia (Lupton, 1995) or the health visitors in Great Britain (Mayall, 1996), were developed to monitor children's growth, survival rates and health status. If a child's health status failed to approach the norms of the time, the failure was attributed to mothers. Children's failure to thrive was, and continues to be, (e.g. Spalding, 1992), equated with poor mothering by others and by mothers themselves.

The consequence of public health structures, such as these, was that it fell to mothers to establish the normalcy of their children. Several authors have suggested that this is evident in mothers' discussions with one another about the details of their children's growth, size and attractiveness (Mayall, 1996; James, 1994). Mayall (1997) argues that it is women in particular who do the work in "controlling, enabling, civilizing and regulating children's bodies and minds" (136). The intended outcome of this work is that children will be prepared to participate in the social and moral order of the wider social group, one day becoming productive, independent citizens.
The bodily character and comportment of children is a marker of their status and their positioning within childhood (Mayall, 1994). There is a social order to childhood, with hierarchical stages starting from infancy, moving to a toddler stage and progressing through adolescence and teens to young adulthood (Alanen, 1992). Each of these stages is bounded by age and attainment of new levels of physical functioning. In western society, we mark the passage to maturity through stages of bodily achievement and control. The bodies of children must come under increasing control before they can become full members of society (Lupton, 1996; 1995). The implication is that parents, particularly mothers, must teach children how to subdue their bodies in order to accommodate institutional agendas. In this study, families engage in the governance of their children by attempting to subdue the differences in the feeding and mealtime situations.
5. THE MARGINALIZATION OF FAMILIES

Children's mealtimes took place in at least two different contexts. Mealtimes occurred within an immediate context, created through the feeding practices, activities and strategies which parents and caregivers brought to the feeding interaction. Mealtimes also took place within a larger context which was influenced by a range of institutional (or systemic) practices. Foucault's notion of normalization was evident in both these contexts, as institution practices subtly "demanded" that children be normalized, and as parental feeding practices attempted to normalize children. This chapter deals with the larger context of institutional practices, outlining the conflicts and challenges they raised for the families, influencing parents' work of caring for their children.

All the children in this study were being cared for in their homes by their families. This reflected a desire on the part of parents to integrate their children into the community, ensure their well-being, and provide them with a normal life. However parents often found it difficult to meet these goals, since school, medical and social assistance structures placed a number of barriers, in the form of policies and practices, in their way. Parents tried to negotiate their way around these barriers by networking with other families, proving their worthiness for support, rearranging their personal resources and making personal sacrifices.

5.1 The deinstitutionalization imperative

Since the 1960's there has been a strong movement towards de- institutionalization of people with disabilities. Community care or independent living has been the alternative for people who would have traditionally spent their lives in an institution. It has fallen to families, especially mothers, to care for disabled family members in the home. McKeever (1997) summarizes the research conducted over
the past three decades regarding family based long-term care. She suggests that these studies have demonstrated that "although caregiving is psychologically stressful, even the most severely disabled people can be cared for safely and economically at home by family caregivers" (McKeever, 1997). Evidence of this discourse, that people with disabilities can be and should be cared for at home, emerges clearly from the interviews with parents. Institutionalization, even institutionally based respite care, is viewed as a personal failure and possibly akin to subjecting one’s child to a painful experience.

The worst thing to think about is putting your child in an institution. I know some mums may not have a choice, but you already have so much guilt. Imagine doing that to your child. I think it’s very, very hard for those mothers to think about doing that to their children.

One mother discussed her anxiety at even using institutionalized respite care for her child.

Like (the hospitals) are great for respite care, but it would be great if you could financially afford someone to come in and give you the respite care in your own home, where you don't feel guilty that your child is in the hospital. Because no matter what, (the hospital) is good...but if I have to go to respite, I'd rather Gary go to that hospital. But he's still not at home, he's still in a hospital environment. And it's not fair to him.

This mother offers little to explain why this environment is not fair to her son. Mothers could just as easily argue that their children would benefit from the institutional environment. Their child would have the opportunity to interact with other children who were similarly disabled. The environment may have shielded their children from discrimination or feelings of difference. Children could possibly benefit from the extra energy mothers would gain as a result of their break from the demands of caregiving. Instead, when parents did place their children in institutions, even for brief periods, they expressed overwhelming guilt and regret. This was evident during observations in one setting that offered respite care. Mothers, picking up a child who had spent several weeks in the centre, would inevitably outline a set of emotionally and physically demanding circumstances that
had been dealt with over the time their children had been in the centre. One mother explained through tears that she was putting her child in respite care for two weeks because she was about to go in for surgery and she could only find baby-sitting for her three non disabled children, back home in Northern Ontario. Nursing staff would often confirm the astounding burden these mothers carried as if to "prove" that they were deserving of some respite. Mothers' distress over putting their children in respite indicated a belief that children should be cared for at home under any circumstances. Mothers themselves enjoyed the hospital's surroundings. They frequently commented on how much fun their children had with the host of teenage volunteers, a greater range of toys, special playtime programs, and high quality video and stereo equipment. Certainly, putting one's child in respite might have actually emphasized how difficult it was to give children that level of stimulation and entertainment in the home. However, mothers did not appear to be "jealous" of or discouraged by the institutional environment. Instead, parents believed that keeping children in the home environment would ameliorate their disability.

I find the kids that are at home that are handicapped are (incomplete thought). I have another friend Jamie, who is eleven and in a wheelchair and all. I find Jamie is more outgoing, being at home than he would be in an institution. He smiles, he's wonderful.. He's the cutest thing in the world.

My son has astounded everyone. None of the medical people thought he would be doing as well as he has. I believe he's done this well because I've been able to give him a loving caring home. I've tried to keep him away from (hospital) as much as possible.

Finally we said we've got to get Tim out of (hospital) and into his home. Because that's no place to raise a child. If he stayed there I think he would have never progressed. He would never be as healthy as he is now.

The belief that the home environment would help children become healthier, may have arisen in part from parents' recognition that institutions were increasingly
short staffed and underfunded. In spite of their facilities, these institutions were not always able to provide consistent interpersonal care to children. Nursing staff in these settings often commented that they relied more heavily on volunteers to make up for reduced staffing as the result of health care system changes. However, during certain days of the week and times of the year, volunteers were scarce; therefore children received varying levels of interaction. Perhaps parents feared that this would have a negative emotional and developmental impact on their child. Another reason parents may have felt their children would fare better outside the institution, was the notion that the family environment provided them with a more normal lifestyle.

Instead of going the institutionalized route which used to be the way this went. But now the system is leaning towards integrating children like Rayna into the mainstream if that's possible. Or at least offering a normalized environment to the children.... You know it's about providing what's best for Rayna, giving her as normal a life as possible.

The link made here, that what is best for one's child is integrating her into an environment that is defined by normalcy, shapes much of the caring work parents perform. Normal environments are seen to produce greater progress in children's health and development. The implication, that becomes more evident later, is that normal environments may produce more normal children. In turn, healthier, more normal children may indicate better care. Keeping one's child out of an institutionalized setting is one step in providing children with the best care possible. Unfortunately, while parents are ready to take this step, they lack the structural supports to allow this to occur.

5.1.1 The struggle for integration

Parents are caught in a dilemma. They must reconstruct their parental roles as defined by the responsibilities abdicated by institutions. They have the responsibility of being the child’s nurse or custodian while at the same time maintaining an "illusion" that their child is integrated into the community.
Although the discourse of community involvement and integration fuel the move to have family based long-term care, the institutional response to the extent of children's disability often limits the degree to which this can be achieved. It is not clear from parents' descriptions of caring for their children or in my observations of this care that community care actually entails consistent involvement or support from the community.

From the time a child was diagnosed with a feeding impairment, if not earlier, families came into conflict with the very institutions that could help them achieve this integration. This conflict affected the family as a whole, and the child's mealtime in particular. Families spoke about the "system", referring in a general way to the various institutions with which they had to interact. More specifically, families spoke of struggles where they "worked the system", by negotiating the medical, school and social assistance policies. Yet these same struggles often revealed that they were, as one family described it, "worked over" by the system.

5.2 Accommodating the system

School policies shaped how children received meals or feedings with little room for negotiation. This was most striking with respect to children's breakfasts. None of the schools which children in this study attended were willing to provide g-tube feeding in the morning. This meant that children had to complete their feeding before their school bus arrived. Most children were picked up by 7:30 to 8 am. Many of these same children received anti-reflux medication, which had to be administered at least half an hour prior to feeding. Adding this to a feeding time of approximately 2 hours, it was not unusual for some children to get their morning feeding as early as 4:30 am. There were several consequences to beginning the morning feeding so early. Children began their feedings while in bed, often while they were still sleeping. Children had their diapers changed, were bathed, dressed
and otherwise prepared for their day while the feeding was underway. There was also no attempt to orally feed children at breakfast, given the limited time available. As a result, compared to all feedings throughout the day, breakfast appeared to be the poorest fit with traditional definitions of a mealtime. In order to arrive at school on time, children were required to receive their feeding in a manner that left them isolated or participating in activities that normally would not accompany food or eating.

Children could receive their lunch or mid day feeding by g-tube at school. All schools seemed to have a policy whereby only nurses or the parent could administer g-tube feeding. Under no circumstances did teachers assist with g-tube feeding. Again this policy had several implications for the child's mealtime. Children's meals or snacks were dependent on the availability of a nurse. In the few schools I visited, one nurse was responsible for several technology dependent children. If a child appeared thirsty or hungry, only the nurse could respond, despite her attention being necessarily divided among several children. While generally children are taught to subdue bodily experience within the school setting (Mayall, 1996; Walkerdine, 1984), it could be argued that these children found their needs and wants subdued longer than their less impaired peers. Other children in the same setting had a larger number of adults upon whom they could call for assistance. This school policy also meant that these children were fed separately from their peers, either in a different part of the lunch room, or in a different room altogether. Just as occurred at breakfasts, children could be fairly isolated by virtue of their g-tube feeding. Mealtimes were less of a social event and became more clinical, requiring the presence of individuals with specialized skills.

Another related issue is that some schools do not provide nursing care, forcing families to dedicate some of their own nursing hours to the school. This was the
case at Gary's school. However, Roberta, Gary's mother, was not able to reduce the nursing hours from her home. Therefore she worked to improve Gary's oral skills to a point where he could eat by mouth and continue attending his school. Most parents in the study would have welcomed the fact that their child could eat an entire meal by mouth, however Gary was restricted to a fairly limited range of foods. As a result, Roberta continued to be concerned that his intake was not always sufficient. Ruth was also affected by the limited availability of nursing at her son's school. Sam's g-tube would sometimes become damaged at school. Although it was apparently very easy to repair, school staff were unwilling to take on this responsibility. Instead they would call Ruth, asking her to come by public transit to the other end of the city to replace the broken device. On a practical level, this lack of school nursing added to the caring work mothers had to perform, using up valuable time, money and energy. On another level, it reinforced and defined their responsibility for their children's care, without giving them the control of how that care should be delivered. Several parents had argued strenuously to get their child into the school system. They perceived the g-tube was the key reason schools resisted admitting their children. Once a child was in the school system, families were understandably invested in keeping them there. This may have been one reason that parents readily assumed the extra feeding work that arose from sending their children to school. Integrating a child into the school system appeared to require families to accommodate to the school's schedule and limitations, rather than the school accommodating the child's requirements.

Families could also find themselves accommodating the policies of other institutions. For example, parents found the medical system to be inflexible to their families' needs. Many of the families' concerns centred around obtaining information, scheduling appointments and securing different forms of therapy and interventions. For example, rural and suburban families, unable to access the large
urban pediatric care centres easily, had an increased burden in maintaining their child's technology. The two families who lived in rural communities, were often unable to receive adequate technical support from their local hospitals. One mother recounted several incidents when problems with her son's g-tube brought them to their community hospital in the middle of the night. Often the hospital staff would send her into the city, claiming they lacked the expertise to deal with her son. On one occasion, this mother became so frustrated with their repeated inability to meet her needs that she demanded to be given a piece of equipment needed for her son's g-tube; then repaired the device "while the emergency staff just stood around gawking".

Families' accommodation of the needs and limitations of the institutions around them may help define the nature of their caring work. Policies affecting children with disabilities living at home convey to parents that they must shoulder the work of institutions. Parents are expected to carry out the work once conducted by medical or nursing professionals. A problem emerges when we consider that the work of medical institutions is to restore individuals to normal functioning (Benner, 1987). One of the major difficulties in considering disability in relation to the medical model has been the impossibility of finding a "solution" to the individual's impaired functioning (Oliver, 1994; Wendell, 1996; Murphy, 1987). As health care moves into the community, and families take on roles that traditionally belonged to health care practitioners, there may be a transfer of conflicts. Parents, given the responsibility of medical institutions, embrace the goal of resolving their children's impairment. Yet this goal is wholly inappropriate for children with severe disabilities, and sets up families to feel inadequate and unsuccessful in caring for their children. As well, parents receive a message through institutional policies, that institutions are of limited assistance in integrating children into the community. Instead, institutions crystallize the norms of the community. Rigid
institutional policies tell parents that the work of integration rests on them. By not accommodating families, institutions reinforce the notion that children must become "more normal" before they can be integrated into the community. The paradox is that they cannot be "normal" unless they are integrated into the community.

5.3 Working the system or getting worked over by the system?

5.3.1 Accessing information from the system

While some policies define and construct parental responsibility by keeping children at home, others seem to recreate the problems of institutionalized environments within the home. Most children in this study required considerable assistance with all activities of daily living. Their feeding impairment often led to increased and specialized caregiving needs. As well, the technological nature of gastrostomy feeding increased the children's unique equipment needs. The task of determining these needs and trying to get them met fell to parents. Accessing home health care support in Ontario is acknowledged to be a challenging and confusing process, and is currently under review (District Health Council, 1997). Parents, in order to care for their children adequately, must learn to maneuver or "work" the various systems which hold resources for their families. This is best reflected in their efforts to secure caregiving support for their children.

All the families in this study were pleased with the quality of caregiver support that they had received. Families spoke in a favorable manner about the various caregivers who helped them look after their children. However, every family spoke of the struggles they experienced in trying to secure home care. Added to this, most families felt that the level of support they currently had was inadequate and that it was not secure for the future.
"Working the system" involved learning how it operated and what it could offer. Other families were often identified, by study participants, as a source of information. Families could provide one another with information about equipment, strategies for feeding, therapy etc. However, families did not only need to know what resources were available to them, but also how to access them. Although members of the feeding clinic tried to provide this information to families, it was not clear how useful this was for accessing these resources. Instead what seemed to happen, was one family would see another with a particular resource and approach them privately.

I really didn't like the idea of having to drag a pole around him all the time. But then I met this family and they had done the greatest things. They had put hooks up all over the house... you see, just like I have here.... and then they could just hang up the feed wherever. You know then he's not pinned down to one spot. They also made this board to go with the wheelchair. You could hang the feed or whatever on it, but you could use it for a tray... and it looked really great, it was this beautiful wood. You wouldn't get anything like that at (rehab centre).

We went to a mall that we don't go to often....And this lady came up, she lived ... somewhere in Durham region and said where did you get that pole. And we told her and she told us her child has a K tube and I didn't hear about that one until recently. And with the K tube you feed continuously. And she's been trying to get one of those T bars like we have but she says she hasn't got it and they said to her you have to ask the Easter Seals because ADP doesn't really fund them, but the Easter Seals will pay for them. But the Easter Seals is getting a little bit iffy and getting on everybody's nerves. But they'll pay for it if they feel you really need it or they feel you haven't taken a thing from them in a long time.

I met this lady... And I saw her with a can of Pediasure. So I said: "what is that?" And she said "You don't get this for Tim?" She said that from the time that her kid was at (Hospital), her social worker came and ordered, she gave her a prescription from the pharmacist. And you don't have to pay for it and this and that and whatever. So then she told me to go to my family doctor to ask him to do it. That they were supposed to do it...to give you. I asked what were the criteria.
...And there's no criteria you know, but because of the child's needs and he's not eating solids like a normal child. The government usually gives this formula, but you have to get it through a prescription.

These quotes imply that there is no central source for families to get help and information in providing care for their child. Several families did mention receiving excellent support from the same nurse who worked at one of the tertiary care hospitals. However her singular assistance was not sufficient to meet the many needs of these families. In the several examples where social workers or hospital staff did try to anticipate the needs of families, they were frequently wrong. For example, arrangements were made for Wilson at the time of his discharge from the hospital, to provide him with a particular type of feeding pump. It proved too difficult to move the pump around his family's multi-leveled home, and eventually Carolyn, Wilson's mother, had to work alone to change these arrangements. When services or information were given to families by institutional representatives, it was perceived to be incomplete and "paternalistic". It could be argued then, that obtaining information from other families avoids these problems. Perhaps it offers more flexibility, families can see different resources in use and choose what is best suited to their needs. However, this means of sharing information, places the burden of responsibility on parents to be constantly vigilant about the resources which could be available. In this way, families come across resources by chance. Other services or resources which might be better suited to their needs may never be found.

5.3.2 Working the system

If getting information about resources was difficult, accessing them often seemed impossible. Parents were pushed to physical and emotional limits before they could get significant help in caring for their children. Families spoke of the need to be one's own advocate in order to approach the level of support required to raise one's
child at home. Although all families were very appreciative of any help they did receive, most describe this process of self advocacy in terms of a conflict. "Battle", "fight", "struggle", "cause a big stink", "cause a big scene" are among the many antagonistic terms most families use to describe their efforts to obtain resources. Cassandra stood out as an exception to this characterization:

I find the government, contrary to what most people say, has been magnificently helpful. Very good. If they really understand the situation and you educate the person that you are dealing with. And you write the proper letters, you can get the help you need and the results you need.

Although these comments are as Cassandra states, contradictory to the popular opinion, they also illuminate the effort needed to access resources. Families can "get...results" if they are prepared to invest time and energy in teaching the individuals who control these resources. Families must continually elaborate the specifics of their situation and why they require particular resources. It is therefore necessary that families have a package of skills which allows them to make their case. Implicit in this remark, is that it is also families' responsibility to do this work if they wish to access resources.

While not particularly critical, Carolyn was less enamored of the social support system, and could highlight its perceived shortcomings.

You have to be your own case manager, because there are no case managers out there. And a lot of families are not in a position to cope with the devastation of a disability...They've got other issues with siblings, family dynamic, family breakdown with the spouse, lack of financial resources. It's no wonder that they can't come out and kind of see the situation positively and have the energy to go out and co-ordinate and fight.

Carolyn herself was fortunate; as a lawyer, she possessed the skills and experience necessary to be able to maneuver the social support system. In addition to actually
liking the work, she had the financial resources to be able to "purchase" assistance with her son's physical care. This left her time to be her son's "case manager", allowing her to advocate on her son's behalf. With the combination of skills, spousal support, time and money, mothers like Carolyn could "work the system" to create the ideal package of care for their children. This is especially evident in her description of the range of individuals involved in her son's care.

He's a little corporation. My guy has no income and he has a staff of nine, ten and he's got programs he... that's just coming to the house. Then at school, he's got to link with their therapists and teachers and deal with their issues.... And the I've got the (rehabilitation centre) therapists, then linking with them and trying to make sure they're linking with the school people. And then we've got the medical community and the follow-up appointments and you know, from nutrition to feeding to sort of allergy/chest clinic to the eye clinic, dental, the audiologist, the neurologist...It's just constant, because he's just got some orthopedic problems we're seeing, you know the orthopedic surgeon, fairly frequently.

Generally however, families lacked some or all of these factors, and were left dedicating the whole of their time to primary physical caregiving. This placed them in an impossible position, because as Carolyn stated, they were left with little energy or time to be able to argue for the resources that might have improved their situation.

While families can make the system work for them, they must initially prove that the system should work for them.

It's a lot easier to prove now, look at the history and the need. But when you're new, they're really...they seem to be less... more reluctant to...or they're less open to provide the support. They want to see "prove it".

There is a period when families must establish their worthiness for support. Given how medically fragile some of these children were, and how demanding they were in terms of care, this interim period is troubling.
Families will take on enormous responsibility before they can "prove it" to social services. For example, Rayna's parents had received home care nine months prior to the interview for this study. Throughout the first two and half years of their daughter's life they had tried to obtain some level of help in caring for her. Their home life had seriously deteriorated before they were successful. Rayna had severe reflux associated with the insertion of her g-tube. Her parents described sleeping with her between them because she was "literally drowning" in her own reflux during the nights. They describe a one year period when Rayna experienced this level of reflux "continuously, off and on, all night long. Every day of her life". In dealing with this situation by themselves, Steve describes:

So we didn't, Adriana and I didn't sleep for a whole year. Yeah that was probably the worst year of our lives. We didn't sleep period, because we were caring for Rayna.

Adding to their stress during this time, the couple was expecting their second child. The pregnancy was classified as "high risk", forcing Steve to leave his job for a year to care for Rayna, while Adriana was hospitalized. Adriana describes her experience of this time

Oh, we were at the most desperate time of our lives at that time....Then Steve went back to work and I had to deal with both of them. And that was loony bin time.

Adriana and Steve were repeatedly unsuccessful in securing home care during this period of time.

Adriana: And I did try to get home care at that time. I tried and I tried, but unfortunately the early interventionist at that time had a problem with her own life. And there just wasn't that connection....(F)or some reason it just didn't develop because I don't know.
Steve: Maybe it wasn't the place and the time...
Adriana: Yeah something. I don't know...

Then as an explanation
(Social services) felt I was able to deal with the situation, but we found that we just couldn't. so finally they assigned another case manager to Rayna.

Rayna finally received home care with the new case manager; by that time she had begun to go to school.

Other parents had similar experiences before they were able to obtain home care services. For example, Cassandra describes becoming quite overburdened before she could receive home care.

I did have trouble at one point, when Star had surgery in 96, where I think I nearly went through a breakdown, because Star went through a lot of bad times...And (social services got home care involved. And they gave me the maximum hours of home care needed. And it really helped, because I was having nights where I was maybe getting two hours of sleep every night, night after night, because she was in so much discomfort.

Missing from the parents' discussions of their efforts to secure and maintain caregiving support is a sense of entitlement. In part this may be because parents have no idea about what entitles them to resources.

We never did (have nursing care in the home). I wonder about that....(W)e suffered a lot... but some people get it and some people don't...That's just the way the system is.

Because there is no understanding for whom the system should work, it is difficult for parents to know what they deserve, or what they have a right to demand. Coupled with this is a sense of tremendous obligation. Even in the most privileged families, both in the study and the feeding clinic, there was a strong sense that one was alone in the process of caring for one's child. Carolyn notes there are "no case managers", and takes on the responsibility. However at no point does she suggest that there should be case managers. Nor does she explicitly note the sacrifices she made to do this work. Just as they were very reluctant to put their child into respite care, parents were prepared to care for their child with minimal support in the
home. This was done throughout financial crisis, family breakdown and even through severely compromised health. Repeatedly, families are told that they should be able to manage their situation. Without caregiving support, families find themselves in an untenable position. They are keenly aware and accepting of their responsibility to care for their child. However arguing for home care admits to a failure in meeting that responsibility.

Ultimately, all families worked the system by rearranging their own personal situation. Families altered or "chose" living situations or relationships that would enhance their access to resources. One of the simplest and most obvious ways in which families did this was by relying on family members to take on a role in caregiving. Several families relied on the child's grandmothers and other close relatives to help with caregiving. This was particularly the case with feeding, where several families identified having involved relatives in g-tube care.

My mom is very experienced in Rayna's care. The only problem is that she can't do it over a long period of time. She can't do it over a whole day. It's too much for my mom, but she is familiar with feeding her by pump. ...And then my mother in law, she's um, she was... she still is a nurse, she just hasn't practiced for quite some time. But she's very good with Rayna, she knows all about Rayna's needs, when it comes to that (feeding) issue, and all her needs, by all means.

Family members and close friends are called upon to supplement the family's home care needs. Sometimes this is in a very direct manner, where family members babysit a child, although, as mentioned earlier, this is rarely done. More often, relatives and family members supplement the mother's care when home care is not available. They watch the child while the mother performs other housework or organizes for her child's care; they may mind a child when a mother is sick or has a nap, or entertain a child when a mother or parent is looking after another child.
Using relatives to help with caregiving is not without its problems. First family members needed to be trained in various aspects of the child's care, particularly with respect to g-tube feeding. This responsibility appeared to rest with the parents, and could not always be accommodated within their already over demanding schedules.

Yeah my brothers and sister are not familiar with Rayna's needs in that area (feeding), we haven't really had the time to teach them.... Yeah, like how to hold her when she's being pumped, that... how to... like when she's refluxing, how to position. That's a lot to learn I think...If you're not experienced I think...How to react to her. Seizuring for one thing....If it were to happen while we were away, someone has to be fully experienced as to how to administer her medication.

It is not only "a lot" for these relatives to learn but is also a lot for family members to teach. Teaching other relatives or family members requires time and skill, both on the part of the primary caregiver/parent and the other family member. It also requires that family members be willing and available to learn these skills. Often, there were a limited number of other relatives for families to draw upon, and in some cases none at all.

Mothers who lacked an extended family to draw upon for caregiving help, turned to the child's siblings. While both study participants and families who visited the feeding clinic, viewed this as a generally positive experience for both siblings involved, they had a concern. Among the five families with more than the one child, there was a perception that siblings were being asked to do or tolerate things that other children would not be asked to do. Roberta, in particular was unhappy about the involvement of her other children in Gary's care

I don't think it's okay personally. I think it's kind of cruel that an eleven year old in a family with a disabled child has to learn all that. But that's like what this woman (a social worker) said. You have a thirteen year old son, let him help you. Why should I? Adam didn't have Gary, I did. Adam should have the childhood that he's supposed to have.
There was a general feeling among these families that their other children were being asked to take on adult responsibility. They helped with feeding, administered medications, entertained and minded their sibling with a disability. Even Wendy, a five year old watched over her sister, Star, while their mother left the room. Wendy's role was to call for her mother should Star reflux or vomit. Appropriately, parents were impressed by the responsibility their other children could manage, commenting on their maturity and generosity. However, they were also concerned that their children were being given an excessive amount of responsibility and that with time they may resent it and their disabled sibling. This concern deepened as siblings grew older and began to develop independence from the rest of their family. Older siblings could no longer be relied upon to give caregiving assistance consistently. While moving into an independent adulthood is a positive and normal experience for siblings, for families it meant an increasing load of care. The loss of this caregiving help was amplified by the greater physical care requirements of an older child with a disability who was now physically larger. This is especially the case in children with gastrostomy, since their improved nutritional status led to a more normal weight outcomes. Mothers, on the other hand, were also older, and expressed concerns about their physical ability to manage this level of physical care.

Families not only required more of their personal relationships in terms of care, but also in terms of economic resources. Relatives and friends were called upon to help families make financial ends meet, or at least to supplement the resources that families had. Melissa and Joshua's situation illustrated this the most clearly.

Melissa had been a private school teacher prior to the birth of her son. She returned to work after his birth, however Joshua's frequent medical crises meant she was often absent. Eventually, her employer recommended that she take a lay-off, since it appeared impossible to attend to her son and fulfill her teaching responsibilities at
the same time. Melissa had thought the leave of absence would be temporary, however as her unemployment ran out and she found herself on welfare, she realized that the situation was more long-term. At the time of the study she was still receiving welfare. In spite of this, she and her son lived on the top two floors of a house, in a moderately affluent, centrally located neighbourhood. Feeding clinic staff were impressed by the level of programming in which her son participated and it appeared he wanted for little in terms of material goods. Melissa made it clear that her son would not have all that he did, if she had relied solely on welfare. A family friend was renting her the apartment, well below market value. Family and friends gave her monetary gifts, and bought Joshua many of the discretionary items children usually want. They took Melissa and Joshua out socially and helped them to go on vacations. Without this support, Melissa felt that she would not have been able to provide Joshua with a comfortable standard of living.

Other young mothers talked about the help that they received from family members and friends, affording them certain amenities that social assistance, or even their incomes would not allow them to obtain. For example, Ruth and Sam's neighbour had given them a television (which needed a new picture tube). He knew they spent many hours alone in their apartment with nothing to do, and therefore recognized the importance of a television to them. Adriana and Steve's families bought them furniture, such as a dinner table, and children's toys. Tim and Patricia described friends who would have "practically given us the shirt off their backs", helping them through rough financial times. These examples highlight the inadequacy of social assistance rates, probably generally, but definitely for families who had a technology dependent child. ADP covers only 75% of children's equipment needs, leaving a sizable portion for parents to cover. At the same time social assistance did not provide enough money for families to buy the dinner table or home entertainment equipment they had received as gifts. While at first glance
these may not seem to be necessities, both these items made a significant impact on specific children's eating environments. The table enabled Rayna's family to sit down with her and join her for family meals, as unconventional as they were. The television, allowed Ruth to join Sam while he was being fed, so that he did not have to eat alone. While families might have some success in getting funds for medical equipment, items that might decrease the social isolation of a child and his or her family could not be easily argued for.

The inadequacy of the social assistance system is further highlighted through the experiences of wealthier families in the study. Although Melissa had worked with a circle of friends and family to provide her son with what appeared to be an excellent quality of care, the differences between Joshua and Wilson were striking. Wilson's family was clearly the most affluent in the study. Wilson's parents were both lawyers, although Carolyn's practice had been considerably reduced given her work with Wilson. While Joshua's home was comfortable, Wilson's was elegant and even luxurious. Located in a very affluent urban neighbourhood, this house was spacious, immaculate and appeared designed to maximize Wilson's interaction with his family. Wilson had his meal in a large, well appointed den which opened off the kitchen. Therefore his parents and caregivers had a choice to sit with him throughout a meal, or work in the kitchen while Wilson looked on from his couch in the adjoining room. The room also was filled with toys, a large screen TV and stereo equipment. While this differed sharply from the physical environments of the children of poor families in the study, the most striking feature was how taken for granted this environment was. For example, all families in the study had a television which was on for some part of mealtime observation. It was often used as a means of entertainment and company for their children who might spend long periods of time in one place being fed. Many of the families mentioned that the television had been given to them as a gift. In contrast, Carolyn, responding to my
impressed reaction to the television, explained that she and her husband loved television, and so invested in a very good set. This comment is indicative of the tone of how they provided for themselves and their son. Although Carolyn described themselves as "not getting rich", they, unlike Melissa, made no suggestion that they had to rely on friends and family to help them supplement their material resources. Instead, Carolyn's income went directly to providing Wilson with an excellent routine of care, consisting of a private school, full complement of therapeutic programming and a legion of paid caregivers, ranging from a housekeeper to a massage therapist. Friends and relatives formed an emotional support network for them, mainly creating opportunities for social contact and offering feedback for decisions which affected Wilson's well-being.

Ironically, Wilson's family appeared to have the greatest level of publicly funded health care support in the study. As discussed earlier, this may be in part due to Carolyn's enhanced ability to access resources. This also suggests that the social assistance provided to families of children with disabilities only addresses need in families who already are in a more affluent and established position, and who are, as we have seen, the best able to access the system. Without adequate financial resources, other families must draw extensively on personal relationships to give themselves some economic and practical relief. Most families of children with disabilities find themselves without adequate financial resources. Young families have not built up the economic base to support the financial pressures that come with raising a child with a disability. Because of the tremendous caregiving needs of their children, one parent, usually the mother, is pulled out of the work force, significantly reducing the family income at the same time that their expenses are increasing. Often family breakdown follows, as husbands leave, unable to cope with their dismal future. Without the husband's income, women must turn to social assistance, becoming entrapped in a downward spiral of poverty. While Melissa
successfully created her own community, relying on family members, friends and neighbours to help make up the economic and practical shortfall, this strategy is risky and uncertain. There is no guaranteed commitment that we know of between Melissa and her support network; any shift of loyalty or friendship has more than an emotional impact. It potentially disrupts her child's practical care. Being at the mercy of the generosity of others also means that Melissa receives only what others are willing to give her and her son. Once again, what children receive is left to chance, rather than reflecting their needs. Nowhere is this more striking than when we consider the inconsistency of support resources among study participants.

Gary's family provided a sobering example of what occurs when families lack both material and social support resources to be able to provide for their children adequately. Gary's mother Roberta, explained that not only had she been employed prior to Gary's birth, but she had also been married. When Gary was born Roberta, like Melissa, tried to continue working. Again Gary's frequent medical crises, often meant that Roberta missed work. Roberta described moving from job to job as she tried to balance a demanding caregiving schedule with work. Eventually, Roberta had to consider leaving work altogether, opting to take courses by correspondence to "train for the kind of job where they're more understanding". One of the difficulties with this plan was that she and her husband no longer had the income to be able to support their family of six. In addition, Roberta and her husband lacked the strong family and friendship network that the other study participants, such as Melissa, possessed. Their families were both fearful of and "disgusted" by the extent of Gary's disability and offered little support to the family as a whole. Their advice to Roberta was to put Gary in an institution. Roberta and her husband found that they had no choice but to "work the system". Like many poor families in Canada (Benoit, 1998), they got a divorce and Gary's father moved into another community where he could find better paying work. Roberta, in the meantime, began to receive
welfare and moved into subsidized housing with the four children. This gave the family a second income, a more reasonable rent and drug benefits, enhancing their family's resources in caring for Gary. It is disturbing to note that their situation may not be unique as Roberta describes:

There is a lot of compromising in a house like this. But like I said, you wanted to know, I'll tell you a lot of families are defrauding the government. Moms are on mother's allowance, Dads are finding another address and still living with Mom. But renting low income rooming houses to find an address. But you have to do it, nowadays you can't make it with a low income family. And I know a lot of families that do that. A lot, a lot of families, But it's not because they want to.

Roberta describes her living situation in powerful terms: "working the system". It is true that she can see an opportunity in the system that can improve her living situation and she does take advantage of it. Throughout her interview there are numerous examples of how she finds loopholes in the system and utilizes them to stretch her meager resources. Mothers, even Carolyn, look at the advocacy work and rearranging work they do in their personal lives as part of not letting the "system work them over". They seem to view their activities, almost as acts of resistance, but what they are resisting is never articulated. Initially we might agree with them. We might look at their resourceful activities with admiration. We might respect their willingness to sacrifice career and lifestyle in caring for their children. Reexamining their actions reveals that women like Melissa and Roberta, and even Carolyn, are not engaging in powerful activities. The only power the family can take is to make decisions or choices which will keep them relatively powerless. Repeatedly, mothers stated that if the government could not provide them with caregiving support, they would be forced to receive or continue receiving welfare. Rather than positioning this as an outrageous consequence, mothers discussed this strategy as if it were a threat. Yet, while they gained in the short-term, families took on new areas of vulnerability.
5.3.3 *Doing the work of the system*

The possibility that parents were not working over the system, but rather doing the work of the system never was raised in any of the interviews. Carolyn, who recognized the extraordinary lengths mothers were forced to take to care for their children, never addressed the lack of fairness in her own situation. By her own definition she was in a relatively privileged position, economically and socially. Yet she was investing enormous energy into securing the best care possible for her son, a level of care that one might expect should be easily available to all.

The time and energy commitment of their caregiving and co-ordination work meant mothers were not able to fully participate in the work force. McKeever (1997) has noted that these mothers have sacrificed income, work experience/career development and pension or retirement savings contributions as a result of their unpaid work caring for their children. Their present sacrifices will endure into their futures.

By accepting financial and material support from others, families run the risk of having their welfare either decreased or withdrawn. Generally any family could expect to find themselves under greater surveillance as a result of receiving public assistance. Families are continually monitored by neighbours and welfare workers. Roberta, for example identified several occasions where neighbours reported her for welfare fraud. On each of those occasions, Gary's father had spent "too much" time with the family, leading neighbours to suspect that he had moved in. To shield themselves even minimally from the gaze of neighbours and welfare workers, families must estrange themselves from their community. This runs contrary to a political rhetoric which encourages families to make up cuts to welfare by depending more on their neighbours. It stands in opposition to the goals of de-institutionalization and community integration of disabled children even more so.
5.4 Summary

Families uniformly felt that institutionalization would not provide a normal life for their child. Yet most of these families faced physical, emotional and economic hardships in caring for their technology-dependent children at home. They made personal and practical sacrifices in their present and potentially their future. It is ironic that as families tried to keep their children integrated in the community - living at home and going to school - they faced a life that distanced their whole family from the community. Families were increasingly marginalized as they negotiated various institutional policies to meet the ideal of community integration for their child. Over and over again, families have to define themselves as being in need relative to their peers. Their efforts to "work the system" - getting a divorce, collecting welfare, seeking donations from family and friends, arguing with medical practitioners - demonstrates how they trade one relatively powerless situation for another. Families find themselves doing the caring work that the "system" once provided, but with considerably less control and resources.

The experience of the children themselves is noticeably absent from any of the parents' accounts of trying to negotiate the institutional policies. In most instances the experience is merely implied. However, the drive towards community integration manifests itself in the children's mealtimes, as will be seen below.

Raising children outside the institutional setting is supposed to protect them from becoming both physically and socially distanced from the rest of the community. If community or policy supports are not available to help minimize this difference, families may create "micro" strategies. These more individualized strategies are enacted within the family and are aimed at dealing with children's difference in the social context that demands normalcy. Taken together with the incredible sense of
responsibility families feel around their children's well-being, the surveillance to which families are subjected and the extent of children's disability, these strategies may speak to extent to which children and their families are distanced from the larger community.
6. THE FEEDING PARADOX

This chapter begins with a presentation of how families described their mealtime experiences. The comments made by families primarily represent their initial response to being asked to describe their family mealtimes and provides the background to the remainder of this and the next chapter. This chapter will go on to explore the feeding practices families chose from as they constructed their children's mealtimes, as well as the limitations these practices imposed on their attempts to normalize their families.

6.1 The meals

The initial response from parents to my request to observe their child's mealtime was confusion. Invariably, I was asked if I understood that the child was fed by g-tube. Parents then suggested that there would not be much to see. As one mother described:

Well you can go to his school if you like, but I don't know what you're going to learn. They just hook him up and leave him there behind the corner. I think he usually sleeps....

Families explained that they did not really have meals. Often parents claimed that they were not like other families, explaining that family members all ate at different times. Each family shared their anxiety with respect to their lack of conventional mealtimes as evident in the following comments.

We're totally dysfunctional around meals. When was the last time we sat together? Well not even Thanksgiving this week. It's crazy, we're all here different times and Tim eats on his schedule, but needs attention the rest of the time.... you can't be together for sure.

We can't really be having meals together. Unless we're at someone else's house where someone else has prepared the meal. And I will be sitting... we'll sit together. And I'll probably be feeding Lindsay and eating at the same time. And I find that stressful. I don't really enjoy it.
We can never have a meal together. We very very rarely eat altogether. Unfortunately, I have trouble going up and down the stairs with her and we do most of eating upstairs, including me. We rarely use the table unless we have company. It's not an ideal at all I know that....Basically we eat upstairs in our beds.

M: I don't know that you could say that we have meals. It's very unstructured...

D: I have Rayna, like I have her now and then I just eat out here (lying down on the couch in the living room with his daughter lying on top of him while her pump is running)

M: Okay, you have to admit... it's not really like that....Because like last night he's eating spaghetti and he's lying down, she's sleeping on top of him and the spaghetti is ... he's holding the spaghetti up unto his fork and letting it fall down onto his tongue so he can eat, because he can't roll it because he's.....

D: You learn how to eat horizontally..

We have no set mealtimes for ourselves, my husband and I both work. My husband gets home really late quite often and so you know, meals at best are on the fly, they're done late, they're done in front of the TV. It's not a you know, "sit down Leave It To Beaver" family where five o'clock, six o'clock, every one comes home and sits around the table and eats.

What emerges clearly from these, and other comments, made by both caregivers and parents, is a sense that families see their efforts to feed their children as falling outside of a definition of what it is to have a normal, functional meal. Yet families persist in creating some type of mealtime for their children and their families. While no family achieves the "Leave it to Beaver" scenario, mealtimes were definitely constructed in relation to this ideal.

6.2 The choice of feeding practices

6.2.1 The g-tube

Prior to the insertion of the g-tube children's bodies could seem "out of control", in the Foucauldian sense. With the exception of Sam, whose feeding impairment developed later in life, the children all had very difficult feeding histories. Parents spoke of the many physical challenges their children had faced, including prolonged
time spent eating, fits of coughing, reflux and vomiting during or immediately following meals and aspiration. One mother described her child's reflux as being so severe that she had to measure the amount of food he had vomited in order to calculate his net intake per meal. As in other studies (Spalding, 1992; Michealis et al, 1992; Brotherson et al, 1996), families mentioned that their children were delayed in growth and development as a result of their reduced intake. Families also noted that their children's intake was of limited variety, since there were so few textures they could manage.

Given the difficulties described in feeding children, one might expect parents to welcome the insertion of a g-tube, since it could potentially minimize their children's discomfort during feeding. The benefits of the g-tube often were visible once it was in place for a short time. As one mother expressed:

I started to realize the g-tube is my friend....At that point when we got the break, we looked back on the year and bottle feeding and the reflux and the vomiting and the insanity we went through....We didn't realize how out of control we were and a slave to this and how awful it was to put Wilson through that until it stopped and we had a bit of time to stand back and look at another way of doing things.

Several families discussed how much easier it was, at first, to feed their children by g-tube. Families were initially relieved at the relative speed and reduction in frustration and fear for both themselves and their children once g-tube feeding was begun. Families also seemed pleased that their children were thriving physically and that they seemed happier and more comfortable. Cognitive progress was also noted; however, while families attributed this to their children's improved nutritional status, they were not completely convinced that it would be maintained by tube feeding alone. In spite of the general impression of improvement among the children, families did not fully embrace g-tube feeding. Instead parents engaged in a number of counter intuitive behaviours around their children's feeding. Rather than choosing feeding practices which would enhance their children's
physical well-being and relieve themselves of some of their caregiving work, parents chose to feed their children in a manner that increased both the physical and emotional strain on the entire family.

6.2.2 Increasing physical risk
Parents repeatedly chose to feed their children in ways that caused them physical discomfort. For example, parents could have chosen continuous feeding for their children, where formula was constantly infused through the g-tube at a very slow rate. The primary advantage of this method was the resulting reduction in reflux. Presumably some children could have a greater energy intake, more comfortably, when continuously fed. Yet only two children in the study received continuous feeding throughout the night to supplement their daily feeding. Instead most parents opted for bolus feeding, either by pump, gravity or syringe.

In pump and gravity feeding, children received a bolus of food or formula within a given period of time. Parents or caregivers set up a formula bag, attaching it to a feeding pump. They then connected the tubing to their child's gastrostomy opening. "Syringing" in the food, involved placing the formula or liquids into a large syringe and injecting it into the child's gastrostomy opening. Joshua could be fed in as little as ten minutes in this manner. Star was also fed by syringe, however her feeding took place over a somewhat longer period of time. Unlike Joshua, Star received her meal more slowly, interspersing each "mini-bolus" with different morning activities. A third child, Lindsay, was also fed by syringe, although less consistently. One of the difficulties with bolus feeding, particularly by syringe, is that a high volume of food was introduced into the child's stomach quickly. This practice has been associated with increased reflux, vomiting and cramping immediately following the meal (Davidson et al, 1995). This occurred on more than one occasion during mealtime observations. Children whimpered in what
appeared to be pain throughout their feeding. Joshua usually became pale and silent during a syringe feeding, and began to cry as the formula was refluxed back through the gastrostomy opening. Rayna reacted with extreme violence to one observed feeding, refluxing through her mouth and back through the g-tube, in addition to experiencing diarrhea. Some children's discomfort was so severe, they had to be held in unusual positions throughout an entire feeding, to relieve their cramping and to comfort them. Parents and caregivers reacted with nonchalance. None found these experiences unusual and none suggested that bolus feeding was problematic.

Oral feeding provides another example of feeding behaviour which subjected children to danger with questionable physical outcomes. There was a continuum, in the group, of g-tube feeding as balanced with oral feeding. Only one child in the study was fed exclusively by g-tube, primarily as a result of his mother's heightened concern with aspiration. At the other extreme, Gary, who still had the g-tube at the time of the study, was being prepared to have it removed. Gary ate most of his meals by mouth and only used the g-tube when he was very sick and when he needed to receive medications. However his mother had said to me privately that Gary still received some meals by g-tube when she was worried he was not eating enough. Lindsay's meals probably represented the most even balance between g-tube and oral feeding, with her meals consisting of both. The remaining children appeared to be fed primarily by g-tube, with families attempting to integrate some aspects of oral feeding.

Oral feeding was often described in parents' interviews as optional. While families tried to integrate oral feeding with meals, they informed me that it was not always possible to do so. Ruth's description of her efforts to integrate feeding by mouth into her son Sam's meals captures the way in which it can be abandoned.
Usually we try things (foods) such as banana, maybe if it's the midday we don't want to, you know, have a bad stomach. But if it's carrots or peas we give it anytime, except in the morning...I'm very busy in the morning and can't give him anything. And if he has a cold or a cough we kind of cut off, because we .. he might aspirate on it or so. But now he (the doctor) says he's swallowing properly. Actually he hasn't had anything by mouth since he came from (the hospital).

Weekday mornings, time spent in respite care, public social occasions and meals in school or day care were all times that parents would forego trying to offer their children food by mouth. Despite the frequent challenges, families repeatedly persevered in offering their children food.

Although I made no attempt to determine to what extent each method of feeding met the children's energy and nutrient needs, the observations, in conjunction with parent and caregiver descriptions, would suggest that only Lindsay and Gary received a significant proportion of their energy intake by mouth. In spite of this, several other families intimated that their children could potentially eat much more than they were currently by mouth. Observations of children's mealtimes and their efforts to eat by mouth rarely supported what parents described. The disjuncture between observations and interviews was probably most striking with respect to oral feeding.

Oral feeding was discussed by parents in very different terms than g-tube feeding. While families stressed the difficulties involved in g-tube feeding, there was a different tone in similar discussions about oral feeding. Families appeared eager to explain their child's ability to eat, and enjoyment of eating, by mouth. Cassandra went into great detail describing how she integrated both oral and g-tube feeding.

(W)hen she's in good health and she doesn't have a cold, I use these little syringes here. Fill them up, pretend, these are 5 cc syringes and I also have 10 cc syringes and I give her in the mouth. Little bits in the mouth so that she can taste what it is that she's eating. Usually I give
her about one and a half to two cc's in the mouth. A bit at a time. She will open her mouth for me most of the time and take it.

As Cassandra's comments illustrate, feeding by mouth alone does not always provide enough energy to sustain some of these children. Often children only could accept enough food to provide them with a taste of what they were being offered or sometimes force fed.

In spite of how little children actually consumed, a theme of danger emerged in families' comments about feeding by mouth. Cassandra alludes to this in the passage above in that she only gives Star food by mouth when she is well. Later she offers her reasoning:

If she's had a cold or a bad night, I won't force feed her. I won't force her to take this, because she is more unstable and experience has shown me that she'll gag and cough a lot more and choke, and sometimes she'll even throw up with one of these in the mouth. She'll just have trouble swallowing it to such a degree, maybe because she's got phlegm in the back of her throat, or she's not able to get all those muscles working in conjunction with each other and she'll just throw up her whole breakfast or whatever breakfast she's had.

This concern was repeated by other mothers, who all told me at different points that they restrained themselves from offering their children food by mouth when they were sick. Feeding by mouth had put all the children in this study at risk for aspiration. Even offering children tastes of food was hazardous, since they sometimes generate more saliva than they can swallow safely. As well, the vomiting described in the preceding quotation also put the child at risk for a compromised energy intake.

Oral feeding was striking in its unpleasantness for children who were observed in this study, as well as those who visited the feeding clinic. There appeared to be no limit to how poorly a child could react to being fed by mouth. The most dramatic reaction came from an adolescent girl in the feeding clinic, who had been using a g-
tube for the past year, following a car accident. Her mother suggested that she might not be amenable to eating everything by mouth. Indeed as the texture of what she was offered became thinner, progressing towards liquids, and therefore more difficult to manage orally (Rogers et al, 1994), the girl became increasingly distressed. She was screaming and trying to throw herself out of her wheelchair before clinicians stopped trying to get her to eat.

6.2.2.1 The absence of children's voice

Although extreme, this reaction was not atypical. Children sometimes demonstrated the same fear when fed by their parents and caregivers. For example, Rayna was offered several spoonfuls of a puree by her nurse at the school she attended, which she vehemently refused. Noting her negative reaction the nurse did not offer Rayna any more. The nurse's reaction stands as an exception, since adults often seemed oblivious, at least initially, to children's reactions to feeding. In another observation, Wilson was clearly interested in his mother's lunch and was quite eager to have a taste of her food. However, after several tastes of sauce from her fork, he began coughing violently. The combination of his physical distress and his spasticity made him so unstable that he could not maintain his seating position. He had to be physically restrained to not fall on the floor. His mother commented that this always occurred, yet she had not been hesitant to offer her son the offending taste. Other children had less physically dramatic reactions. One child did not open her mouth while her mother gently pushed a small syringe between her lips. The child made no attempt to manipulate the food in her mouth, nor did she appear to attempt swallowing the food. Instead, the food slowly escaped down her chin.

What is particularly interesting is that while there could be any number of reasons why children did not eat by mouth, their refusal was not one of them. Similarly,
while a number of problems were raised with g-tube feeding, the negative physical impact of bolus feeding was not really presented as a reason to discontinue that particular feeding practice. Children did not seem to derive much pleasure from either feeding route. In fairness, there were instances where parents did attend to children's reactions. Parents noted when children seemed pleased or interested with a particular taste (although this reaction was only observed twice throughout the study). Some parents interpreted their children's behaviours, such as smacking their lips, as a sign that they were hungry. Many parents warmed their children's feed prior to giving it to them, as they believed it would provide a more comfortable sensation as it entered the stomach. However, the same parents expressed uncertainty about what their children "really thought" about the meals. A consistent reading of children's reactions and perceptions of food, feeding and mealtimes, rarely informed feeding practices, in spite of the fact that these very practices appeared to have a significant negative effect on children's physical and emotional well-being. The implications of the absence of children's "voice" in determining their mealtime context will explored in the final chapter.

6.2.3 Medical disapproval

The practice of oral feeding was even more puzzling when one considers how it was sanctioned by the medical community. Eating by mouth can carry a serious risk of aspiration for children with the level of feeding impairment seen in this study (Arvedson et al, 1994). In the clinic setting, particular attention was paid to identifying textures children could safely eat. Practitioners tried to impress upon families that even if their children were not coughing or choking on food they could be aspirating silently. In this study, families appeared to have a good understanding of this caution from the medical community, however they still proceeded in trying to feed their children, even if only minimally.
Although some feeding practices appeared to put children at no immediate risk, they still drew disapproval from the medical community. Five children received at least some homemade formula, or highly pureed foods through their g-tubes. Like any aspect of children's feeding, there was a range of types and amounts of food provided. Some only were given homemade formula to supplement the commercial formula they were prescribed, while others were fed homemade formula exclusively through their gastrostomy. Mothers who used pureed foods through the g-tube all mentioned that they understood that medical practitioners did not approve of this practice. In my interview with Patricia regarding her son Tim, she initiated a discussion about using pureed foods through the g-tube. When I asked her what made her decide to feed Tim in this manner, she immediately responded "I know I'm not supposed to." Several health care workers had told her that this practice may clog up the tube. Most families, whether they used pureed foods or not, shared a concern about tube blockages. These blockages meant interrupted and longer meals or feedings. As well, any damage incurred to the equipment as the result of "improper use", such as the use of pureed foods, was not covered by social assistance benefits (McKeever, personal communication). This not only puts financial strain on the family, but strongly reinforces the notion that professionals do not approve of the practice. Cassandra received a similar message when her daughter was given a g-tube.

(T)hey told us the only thing you should give through the g-tube is the stuff that they recommend, that would be Carnation Good Start or the Pediasure. Foods that I assume that the studies with g-tubes have shown that there's no problems, that they're compatible with g-tubes.

In spite of this Cassandra only fed her daughter homemade purees through her g-tube. In fact, one of her key reasons for participating in this study was to discuss making one's own formula or food. She believed that more families would do this if they could.
Ruth also fed Sam homemade formulas through the g-tube occasionally. Unlike Cassandra she was much more hesitant to share this practice in her interview. Her caution was understandable given her observations in a hospital.

Well this one guy used to come in and his tube was always hopelessly blocked. It turned out that he was getting pureed foods through the tube. Oh they (the hospital staff) was mad at them people.

Contrary to family's fears, the staff in the feeding assessment clinic were open to families feeding their children pureed foods through the tube. The clinic members tended to have greater fears regarding oral feeding of children when there was a risk of aspiration. However, families' fears about the reaction medical professionals probably would have been confirmed in other clinical settings. During several observation sessions, health care workers were heard expressing concern over not really knowing what these children were being fed. Concerns rested in several areas. First it was difficult to ascertain the exact energy and nutrient intake of children fed in this manner. Given the compromised nutritional status of these children when they were first given a g-tube, this concern was warranted.

Equipment breakdown was also a concern, especially tube blockage. In school lunch observation, a child's tube had blocked and his feeding had stopped. It was not certain how long the tube had been blocked, however it took the nurse approximately 15 minutes before she could clear the blockage. This, in addition to the time which lapsed during the blockage, lengthened the child's feeding time. In turn, this limited his participation in other activities. A final concern expressed by health care workers was the level of sanitation required for this practice. There does not appear to be a strong basis for this concern in the literature, nor is it clear that there are clinical practices guidelines that help either parents or health care workers with these issues.
6.2.4 *Time and energy investment*

The fact that mothers prepared food for their children in the face of perceived disapproval from the medical community is particularly interesting given the amount of work required. In interviews parents tried to minimize the work required to prepare pureed foods for their child, preferring to emphasize the challenges faced in maintaining the g-tube; yet the task seemed labour intensive. Ironically the extent of this work might address the concerns held by health care professionals.

One mother’s description of how she prepared foods for her daughter illustrates the amount of work required. She had taken an alcove and linen closet in her hallway outside the bedrooms and turned it into a second kitchen. A full sized refrigerator was filled with pureed foods she had made for her daughter. A counter built in beside the refrigerator was covered in bottles of vitamin and mineral supplements and homeopathic remedies. The surrounding shelves were filled with feeding and cooking supplies. A small microwave was tucked into a corner. A hand blender was plugged into a bathroom socket, where one might usually expect to see a hair dryer or an electric razor. When the mother brought me into the area she began showing me slips of paper tacked to a bulletin board, each of which held some information about her child’s feeding schedule and meals. She began to describe her recipes for her daughter’s meals.

*We made a batch for her, oh it fell down somewhere, oh here it is. This is how I know what she’s had. For example, January 30th, we made a batch of food for her.*

*These are the batches of food for her in here (opens the refrigerator). Okay? And I thaw them out. They were just made. This one was made February the tenth. Most of these were made February 10th, and I freeze them, and she usually goes through two a day. In that batch of February the 10th, we have white onion, carrots, chayote, pepper, sweet potato, potato, salt, ginger, chicken broth, spinach, broccoli. All put together and there’s a batch from January the fifth. Split green peas, broccoli, white onion, potato, zucchini and olive oil.*
When preparing the food:

What I will do is I’ll bring it out of the fridge and I take the blender.... you see how it looks now, I’ll just show you so you can get an understanding of this. You plug the blender in, and you see the consistency of it right now? (Blends it) No it’s too liquidy. So now you add the Pabulum and the Pabulum thickens it right up.

Although Cassandra goes through some steps to feed Star the extent of the work she invests in the process is largely implicit. Earlier, Cassandra had explained that all her purees were made from fresh ingredients, including on some occasions her chicken broth. One can easily see from the two batches of food she describes above, that her child may actually be receiving a greater variety of foods than the average child. The steps involved in making this type of food include vegetable preparation, cooking and pureeing. Given the manner in which her freezer and refrigerator were organized, Cassandra had additional tasks once the food was cooked. She portioned the food into smaller containers, labeling each, freezing the batch as a whole and recording its contents on a master schedule. Meal preparation did not end there. As she demonstrates above, when she has to use one of these batches she must still thaw the food, reblend it, add Pabulum and then actually feed it to her child. Deconstructing her work in this way provides only a partial picture of her work. Every component of meal preparation is lovingly thought out. Even giving her child juice is a considered activity. Cassandra buys "top of the line" juices, straining them to remove excess pulp, mixing them with water when necessary and clearing any blockages with carbonated beverages when necessary. Still other decisions have to be made concerning what to feed through the g-tube. For example, when Star has a cold, Cassandra rebalances what she will be fed.

I do give her milk occasionally now and I give her Pediasure everyday except when she's got a cold. I cut out the Pediasure, like now she’s been sick (to minimize mucous production), I don’t give her Pediasure in the morning. I give her chicken broth with Pabulum and water. Lots of water and lots of chicken broth, and once the cold is over, she's back to Pediasure.
These comments clearly demonstrate Cassandra's commitment to her daughter's well-being. The extra work and medical disapproval involved in feeding her daughter foods receives relatively little mention as compared to the benefits it confers to her daughter's well-being.

The work involved in making the formula may be work in addition to the work of feeding the rest of the family. It is unlikely that all family members would eat the same range and variety of foods which made up the purees. Mothers, already burdened with the responsibilities of care, faced double work for meal preparation.

6.3 Understanding the feeding paradox
In every case, families engaged in feeding practices which had a negative physical impact on their children, whether it be the temporary discomfort associated with syringe and bolus tube feeding to the very serious risk of aspiration associated with oral feeding. Yet parents were clearly dedicated to their children, as demonstrated by the significant investment of time associated with these practices. At times, as in the case of using pureed foods through the g-tube, parents even placed themselves at financial risk. Their practices might easily lead them to be labeled, by health care practitioners, as non-compliant, thereby risking disapproval from the very institutions which might afford them access to resources in the future. Feeding children in a manner which was clearly harmful appears paradoxical when viewed against parents' tremendous sacrifice and commitment to their children's well-being. This willingness to place one's child and oneself under the burden of physical strain and risk can be understood only if we consider the lack of viable feeding practices available for their children, especially in light of the powerful symbolic meanings and social consequences associated with each practice.
6.3.1 The problem of difference

In many ways, g-tube feeding forced parents to continually confront how different they and their children were. Children's g-tube use prevented them from attending schools, participating in food related activities with their peers or having a meal around the table with their families. Children's g-tube use could also be visibly stigmatizing as they were continually accompanied by a set of feeding equipment or visibly and audibly expressed pain and discomfort with feeding.

Sometimes the g-tube did not fully resolve all the difficulties arising from the child's feeding impairment. For example, reflux often still continued even with the insertion of a g-tube. Rayna's parents described sleeping with her between them when she was on continuous night feeds, so they could wake up when she refluxed during the night. Although g-tube feeding could ensure that children had a greater intake within a shorter period of time than oral feeding, some children still required a long period of time to complete a meal. Some mothers talked about rising at 5 am, 4 am or even 3:30 in order to give their child an anti-reflux medication and begin his or her feeding before the school bus came. Children could take up to two and a half hours to finish a meal by this method. The continued existence of problems related to the feeding impairment may have made it difficult for parents to always see the initial advantages associated with the technology. Even Carolyn who earlier referred to the g-tube as her "friend" could list a number of complaints.

Among parents' complaints were new problems introduced by the use of a g-tube. Although most pumps can be run by battery, often the pumps had to be plugged to an electrical outlet, sometimes limiting the places children could have their meals. Pump feeding was characterized by many interruptions, as batteries ran out, the tubing became clogged, the child "slowed down" the rate of flow, or the child
experienced physical difficulties, such as coughing, reflux or vomiting. Several families also mentioned their own or other children's experiences of having a balloon type g-tube. This type of tubing seemed to carry its own difficulties, bursting when the child rolled on the floor and coming out at inopportune times. The device had to be repaired before families could go on to feed their children. As discussed earlier, parents were often responsible for these repairs, adding to their work of care. Parents of the these children, as well as those who came into the feeding assessment clinic, expressed ambivalence at putting their children on continuous feeding, despite the fact that their child might have been more physically comfortable with it. It was especially evident in clinic discussions that parents felt that continuous feeding would limit both their own and their child's freedom. This was the case in one discussion with the clinic where medication had failed to correct a child's reflux.

I don't want to have him on the tube all the time. What kind of life is that, always dragging the pole behind him? Can't we change the formula or something....I mean, I can handle him on the tube at night, but if we have to start doing this during the day too, it will be awful.

Continuous feeding meant that the tube would become a continuous visible icon of the severity of children's disability, as well as a practical inconvenience as families would have to constantly transport it. Generally the clinic staff were sympathetic with families' concerns and seemed to only encourage this method strongly when children were initially given a g-tube and probably in medical crisis.

Some children did not adapt well to the type of gastrostomy they were given. Wilson, for example, had constant infections at the stoma site. Star's mother also made reference to using citric acid to treat minor infections at the g-tube site. The most striking example of this new problem was offered by Tim's parents. Tim's original site apparently was placed so high that it rubbed against the bottom of his
sternum, creating a severe infection, eventually leading to septicemia. His parents described how Tim coped with this infection.

M: (T)he g-tube was always infected, he couldn’t go on his stomach.
D: His site placing in our opinion was wrong.
M: Wrong. Wrong place. The site so he got to....
D: It wouldn’t heal. Every time he tried to crawl it would be so sore or so painful, that he would just give up and move on his back.
M: Yeah. He would burn off his hair, because he found a way to mobilize, by on his back.

These new problems created by the use of g-tube feeding have been acknowledged in other studies (e.g. Naurekas, Kauffer and Christoffel, 1994). Like the feeding practices that parents engage in, they add to volume of caring work and they inflict physical and perhaps emotional strain on children. The difference between the practices that parents choose and those advocated by the nutrition community are related to their social consequences and symbolic meanings. G-tube feeding maintains and contributes to the perception of children’s difference or abnormality. Patricia’s comments about how her son began moving around on his back because of the infections around his stoma site illustrate how this can occur. As the result of the g-tube insertion, Tim became increasingly different. He stopped "crawling", taking on a more unusual form of mobility. The hair loss on the back of his head may have given him an odd appearance. His compromised health as the result of the infection, meant he lost the limited oral motor ability he previously possessed, forcing his parents to stop oral feeding for a time. In sum, after the insertion of a g-tube, Tim becomes more obviously "not normal". Similar consequences are incurred by other children. The g-tube fails to help children achieve the bodily control that marks their status as normal and healthy. Parents respond by constructing children’s meals in the effort to reframe their children’s difference in relation to social norms.
6.4 The reconstruction of mealtimes

Researchers have documented how mealtimes are linked to western notions of family well being and function. Mary Douglas (1975) in her work "Deciphering the Meal", discusses how the meal acts as a focal point for the family. The gathering of the family around a table facilitates communication, ensures that family members do not engage in other activities. Only family members and other intimates can come together around the tables, thus mealtimes help draw boundaries between the family and the rest of the world. Who is "at the table" becomes a metaphor for who counts. The notion of the "proper meal" also has been explored by several researchers. Strict rules appear to exist about what constitutes a good and "proper meal" (Douglas, 1975; Murcott, 1982; Charles and Kerr, 1988; Murcott, 1997). Meals must be comprised of specified foods, tastes, textures and colours. The "proper meal" is seen as critical in maintaining the health and well-being of the family members (Murcott, 1982; DeVault, 1991; Mayall, 1996; Murcott, 1997) Although few families could in practice achieve all the requirements of the proper meal, it remains a powerful feature of women's work in maintaining the integrity of their families. It is not surprising then, that gastrostomy feeding, which deviates so markedly from western conceptions of a meal or food, should become a site of normalizing practices for families. The use of a g-tube keeps the child outside the family unit. As a result, g-tube feeding is representative of how disrupted family life has become.

Parents ignore the effects of feeding practices on their children's bodies and their own, in deference for the symbolic and social implications of each practice. It is these implications which reflect parents' concern for the welfare of their children. For example, feeding children pureed foods means children are able to eat foods perceived as less "toxic" and more healthy, thus maintaining and enhancing their future health. Some practices, such as oral feeding, were perceived as helping
children become more integrated into both the community and their families, enabling them to attend integrated schools and camps, other children's birthday parties, family gatherings, family outings and participate more fully in all those settings. In turn, children's improved health and integration may relieve families of their reliance on institutional supports, freeing them from the sacrifices they have had to make. More importantly, they can help families as a whole become less marginalized.

Ultimately these symbolic meanings and social consequences softened the perception of difference with respect to children and their feeding requirements. In the process of constructing their children's meals and feeding experience, families drew from options which diminished the difference, or at least the implications of difference, between their children and others. Practices which might have increased difference were avoided. Therefore the mealtime context for each child reflects parental negotiation of the differences brought about by the feeding impairment and subsequent use of a g-tube.

The construction of each child's mealtime context represented parental efforts to reframe their child's difference in relation to social definitions of normalcy, particularly with respect to mealtimes and eating. As will be seen in Chapter 7, although there was a unique mealtime context for each child, there were clearly four main strategies families employed in mealtime constructions. These included "hiding difference", "minimizing difference", "viewing difference as temporary" and finally "viewing difference as normal". Any one of the feeding practices described above could be used to construct more than one strategy, however the rationale for its use varied between strategies. No parent chose exclusively from
one strategy, sometimes hiding their child's use of a g-tube, other times defending its presence to others.
7. MEALTIME CONSTRUCTIONS

7.1 Hiding difference

The first strategy evident in children's feeding, is that it could be hidden. In many ways this was the most straightforward approach. Parents acknowledged that their child's feeding and relationship to food did not fit into widely held norms. Therefore feeding and mealtimes tended to be covert events, for everybody in the family.

Parents brought up a number of examples where other families or other family members "couldn't handle the g-tube" and as a result "hid the tube". Several times, parents discussed the use of syringe feeding, suggesting that it was done in the place of the more obvious pump or gravity feeding. As explained in Chapter 6, pump or gravity feeding often were more visible, given the need for either a pump attachment or the T-bar attachment on the child's wheelchair. Syringe feeding could often be done more quickly and discreetly as Ruth's comments suggest.

Well for some people they can't handle the g-tube because it’s not normal. This one mother I know, she doesn't want anyone to know her kid has a g-tube. So you know that kid has to get some food if they are out. With Sam, when we go to Walmart I just hook up the feed while we all sit and have lunch. Not this lady, she brings a syringe and she feeds her kid in no time flat.

Ruth contrasts this parent's feeding strategy with her own more open style. While syringe feeding, or more covert feeding in general, could be interpreted as a desire to give one's child more privacy or to create a faster, more portable feeding method, parents in the study shared Ruth's analysis. Covert feeding was often seen as a reluctance on the part of the parent to reveal their child's disability to others. Cassandra spoke disparagingly of her husband's difficulties in accepting Star's g-tube use.

Oh he never got used to her eating like that. If they're out and she's hungry, there's just no way he would give her a feeding. He's too
embarrassed to do it in public. Not me. I say screw that. If she's hungry, if it's feeding time, she gets her food. It doesn't matter where we are.

Again Cassandra, like Ruth and other parents, suggests that she has a more open style in terms of g-tube feeding. However parents often engaged in similar practices as the parents they described. Parents turned their children to face a corner while they were fed in public. During observations in public places, families tended to choose more secluded tables, so that we would not be "there for everyone to see us". Another parent covered the T bar with her coat stating that she did not want everyone to see the feed. Many times these small practices contrasted sharply with the parent's description of other feeding practices. For example, Mary spoke of how she was trying to move to a point where she could see Lindsay's g-tube use as different but normal for her, she later contradicted herself.

And for the tube feeds...I did those in the bedroom. Because umm it's just umm, I'm comfortable myself..but...most people might... in case they're not, it's better just to make it private...It's for others...

Her hesitating description of giving a tube feed to Lindsay in the bedroom during a party suggests that even though she may wish to perceive her daughter's use of a g-tube as normal, Mary is unprepared to be public about the feeding method.

In part the fact that parents drew a distinction between themselves and the parents they described may be based in a fundamental difference. Often when parents in the study described this strategy, they described it as part of the other parent's larger difficulty with revealing any aspect of the child's disability. For example Roberta began by describing how Gary's father refused to participate in any aspect of his son's feeding, expressing extreme discomfort with the clinical nature of his son's care requirements. As Roberta discussed this, the discussion broadened to illuminate her husband's difficulty in accepting any part of his child's disability. According to Roberta he still believed that his son could be "fixed".
Gary's dad said (when he found out about his diagnosis) with the missing part of his chromosome, his instant remark was "well add it in, fill it in.

This lack of acceptance was relatively benign compared to the despair of other parents. In a similar manner as Roberta, Ruth described how another mother would not feed her son in public. Eventually she described how every aspect of her child was hidden from her community.

This one mum... She's told none of her family about this child. The only people that know were professionals that were coming into the home. At first she knew one day he would become normal. But he was missing part of a chromosome so no he's not going to be normal. She used to tell me that when she took the taxi down to (hospital) she would wish the taxi would drive off the road and.... well you know.

Parents' choice to feed their children covertly, seemed to be part of a larger strategy to acquiesce to norms around feeding and eating. Parents recognized the gulf between the limitations of their child's disability and these norms, but do little to minimize the distance between the two. When using this strategy parents do little to actively limit the marginalization that results from having a technology dependent child. As occurs with each strategy, parents realize that their children cannot fit with societal norms. However there may be times when families cannot communicate their child's potential for normalcy, or when they cannot minimize difference in some other way. Finding it impossible to follow the discourses which accompany deinstitutionalization or family based care, families attempt to hide their children's difference. Thus, hiding difference appears to be an interim measure when no other practices are possible.

7.2 Minimizing Difference

This strategy entailed efforts to minimize children's differences surrounding their feeding. Parents sought opportunities which afforded their child access to a more normalized experience during mealtimes and feeding. Aspects of able bodied
children's routines and environments were imposed upon participants' feeding and mealtimes.

This strategy reflected parents' acknowledgment that there were many aspects of children's feeding which were not perceived to be normal. Families recognized there were a number of aspects of their children's feeding which were highly clinical and therefore symbolized the extent of their disability. The use of formula provides a clear illustration of how this occurs. Formula tends to be viewed as not a "real" or complete food. Formula, like the g-tube is framed as part of the clinical intervention. Through conversations about its cost, parents came to view formula as a medication.

7.2.1 Formula versus food: An illustration

All the parents raised the cost of formula and when relevant, their relief at the fact that it was covered by their benefits. Cost figured as a consideration in making decisions about what to feed one's child, even though other options did not always appear to be available. Timothy's parents paid $370 a month for formula because they had difficulty obtaining coverage. Meeting the cost was a serious hardship in light of their "economically tight" income status. Patricia's comments point to the extreme outcome of the high cost of formula.

Yeah, you have to deny yourself a proper meal to buy the child formula. I can't give him homo milk, which is cheaper. They say you have to buy the can of powder to give it more calories, so that it tries to boost up him weight.

As Patricia's comments illustrate, the more economical alternative simply cannot provide her son with enough energy or nutrients. Even when families received assistance, the cost of formula was still a concern as Ruth's comments illustrate.

Now the first time we changed the Isocal was because of that Bob Rae. He passed, that you had to pay 91 cents extra for a tin. Now, when he passed the Social Contract and so on, we had to pass to the other.... Now the pharmacist tells me its up to me 'cause all of these the
government pays for. But he says...I say to him "do I have to pay an extra charge for the Isocal?" He says the Isosource I have to pay an extra charge... but its just that the pharmacist didn't charge me...

In this instance her pharmacist was absorbing the extra charge of a specific formula her son was using. Roberta 's concern with the cost of formula was also evident as she and her son's caregiver, Jan, discussed her drug bills.

R: You really have to find a good pharmacist, and when you think about it, I think I'm already at about two thousand dollars worth of drugs this year so far, that have been used just on Gary.

J: It could be more, because of the Pediasure.

R: Oh yeah, the Pediasure.

J: The Pediasure is about $50 or $60 per case. We go through...

R: ...two cases per week.

J: Or more.

The comments made by Ruth and Roberta and Jan, not only highlight the high cost of formula, but also construct a parallel between the formula and medications. Ruth discusses the formula with her pharmacist and Roberta and Jan raise the cost of Pediasure in the context of a discussion about Roberta's annual drug bills. Their discussions position the formula as another type of medication. Talking about the cost of formula not only marks the way in which formula is equated with medication but also contributes to this particular construction. Although families never make explicit reference to this, formula's cost is considered in opposition to food or milk in Patricia's comments or in addition to the medication. Given the high cost of formula in comparison to children's traditional food, it is not difficult to conceive how its cost contributes to an image of formula, as highly specialized, but not a real food. This construction of formula is evident as Roberta described the difficulty Gary experienced when first put on the g-tube.

R: When he was at Sick Kids, we noticed that he was projecting (vomiting) a lot, even with the g-tube in place, so he couldn't handle a lot of food, not more than 60 mls. of feed and that he couldn't tolerate.
J: So we had to lower the dose.

The use of the word dose is interesting here. It refers to the rate at which the formula is infused through the g-tube. Like all parents in the study, Roberta uses both the words "food" and "feed" in reference to what Gary is given through the g-tube, suggesting that perhaps families definition of formula is not rigid, but shifts along a continuum of viewing formula as a food or as a medication. Where families situate their discussion along this continuum may be influenced by external messages. It is the health care worker Jan who actually uses the word dose to describe the amount Gary is fed. At different points, families mentioned how prescriptions had been made for formula. Again this contributes to its image as a drug or medication. In the clinical setting, formula appeared to be similarly perceived. Doctors and dietitians also referred to the prescriptions for formula, necessarily looking at formula choices in terms of how well it was tolerated by the child. While we might consider food choices in the same way, formula choices are considered only with respect to how well tolerated they are by the child. Ruth's comments about Sam's formula are typical.

Sam switched from Isocal to Isosource. And now he's back on the Isocal because the Isosource gave him really runny bowels. And that's really soft bowels. The Isocal is really not that bad, but I'm really watching it because sometimes it does get constipated. Dr. X says I could mix it with the Isosource if it got too constipated.

Pureed vegetables would have been a cheaper alternative, however the clinical nature of formula privileges its use as a solution to a clinical problem.

Formula does not have a clear cut symbolic meaning for families. Sometimes formula can be thought of as food in addition to medication. When I asked one mother directly if she ever referred to the formula as food or if she referred to g-tube feeding as eating, she admitted that she had never really thought about it previously. Pondering the question she said that she would probably like to do that
more in the future since it was her son’s food. Most commonly, parents and caregivers referred to mealtimes by the type of meal that it was (lunch, snack, dinner), "feeding time", "your (his, her, the) g-tube" or "tubey". While this may not seem exceptional, other children and even adults referred to their food by its name. For example when I observed Sam’s and Lindsay’s meal in their schools both children were fed with children who ate orally with assistance. During both lunches, children fed by gastrostomy were told that it was their lunch time and that it was time for their g-tube. Other children in the same setting received considerable discussion about their meal.

Look Frannie, what did you get for lunch today? Wow, you got Sailor Moon pasta! Look at those shapes. Can you recognize anything? .... What did your mum give you for dessert? Oh ... your favourite, chocolate pudding. Okay so after you eat your lunch, you get your pudding.

This line of conversation continued throughout that child’s lunch, as she was encouraged to "comment" on her food. She was asked repeatedly if her food was good, if she enjoyed it, if too much was on the spoon, if she wanted more and so on. In contrast Sam, and the three other children who were g-tube fed were told that it was lunch time, told that they were going to be "hooked up" and received no conversation about the formula. Of course it is not clear that there could be appropriate conversation one could have regarding the formula, or that the child would want it. However, in some settings the use of formula curtailed children’s interactions with others. As well, the limited nature of the discourse concerning formula, may distance our thinking about it even further away from food.

7.2.2 Constructing the normal meal

In keeping the mealtime "as normal as possible" parents tried to minimize this social and symbolic distance. Parents tried to create a mealtime environment which mimicked that of a normal child. For example, children were included in typical
mealtime conversations about food. Although formula, was being fed to children, it is referred to as food.

(At dinner we say) "You're hungry. It's suppertime." So it's not something that we're trying to hide, where you know, it's just done and it's put there, and it's just quietly grabbing the tube and hooking him up. We do make a focus of "here it is, we're going to get your feed."

Carolyn's description of the conversation that took place around her son's mealtimes, are in contrast to the many silent feedings observed, where comments seemed directed at the technology rather than the child him or herself. In one institution, feeding times were announced to children by telling them it was time to be "plugged in". This referred to the fact that their feeding pumps needed to be plugged into an electrical socket. In contrast mothers and other caregivers who, like Carolyn, talked to their children during meal and feeding times, tended to describe the process to them. Sometimes they asked if the child was hungry, but generally steps of the food preparation process were recited to their child. "That's right, I'm warming up your food!". Carolyn herself later wondered if Wilson actually understood what was being said to him. She had no idea whether he knew what hunger was or if he had ever experienced the feeling. Her conversation with him during his meal was presented as a safeguard. It ensured that her son had some of the experiences typically associated with a child's mealtime.

Carolyn places the g-tube feeding within the conceptual structure of a meal, in her discussion about feeding Wilson.

He's been getting a morning feed, a lunch and a dinner feed, and we run that 200 ccs an hour, he gets about an 8 ounce bottle, maybe 250. You know we're not one of these families where he has to get just 250 or just 260. You know the feed is just what the bottle is, sometimes its more full, sometimes it's 240, sometime 280. it's just like how a normal kid would eat. What you get is what you get.

Carolyn constructs the feed as if it were an eaten meal, by recognizing that a "normal kid" would have some variation in amount of food offered in each meal. Although
she maintains traditional norms with respect to mealtimes, she challenges the g-tube feeding as a purely clinical procedure. Wilson's process of being fed, sheds some of the precision and structure usually associated with g-tube feeding.

This effort to lessen the technological or clinical nature of g-tube feeding is also apparent in parents' efforts to make their children's formula. Cassandra discusses her rationale for making Star's formula

Well I know a lot of people say that it's (making one's child formula) is for psychological reasons for the mother. But I think it's more than that, I think we need... you know evolutionary wise we need food. Oh I know those formulas give you everything to sustain life, but what if there's enzymes or something that's missing? This way it's just more normal evolutionary wise.

Even though her daughter's method of feeding may not address needs for sensations such as taste, pleasure or comfort, Cassandra's efforts to use homemade formula, also removes some of its clinical characteristics. The implication in Cassandra's comments is that as her method of feeding becomes more natural, it also becomes more normal. For instance, there is a greater opportunity for commensuality during meals, as both Star's sister and Cassandra ate similar foods to Star (although not pureed). Although never openly stated, homemade formulas may have fostered a sense that the g-tube fed child was included in the family meals. This may have also been the case for Patricia and Ruth who both had immigrated to Canada. The purees they fed their children contained foods indigenous to their countries of origin, and may have given them an opportunity to impart a sense of cultural identity to their children. The act of sharing foods allows the family a normal practice in relation to mealtimes.

Although families often spoke of their trouble in creating a normal family meal time environment, one way to remain as normal as possible was to integrate g-tube feeding within the pattern of mealtimes common to Canadian society. The primary
way in which families thought of achieving this was by attempting to recreate an idealized family meal. Parents strove to have meals where they could sit as a family around a table.

Martin (Rayna's younger brother) now, because my mother bought us this table, which is great, because now what he does is he sits beside dad, he eats besides dad. Just like as though we were a normal family. He will sit here in his own little chair, and Steve will be over on the other side and hold Rayna like that. And I eat there, he eats with daddy. So there's still a little bit of that structure I guess.

These comments appear to contradict earlier claims to "no mealtimes". However it is important to note that this family ate their meals in the living room, around the coffee table. This among many other aspects of feeding their daughter accounted for their sense that they had only approximated mealtimes. For other families, there was a concern that the child be able to partake in the social aspect of meals.

Cassandra spoke about how she wanted Star to be able to eat at MacDonald's like other children. She convinced management at the local franchise to install hooks at several booths, so she could hang her daughter's feeding bag. Cassandra also carried along a knapsack full of supplies that would enable her to feed Star in almost any setting. Among the items, Cassandra included safety pins, paper clips, elastics and bobby pins, so that in the absence of a "hook" she could feed Star in any setting.

Patricia discussed how she changed the number of feeds her son Tim received each day. Ideally Tim would have received six separate feedings per day, however Patricia decreased the number to three much larger feeds. When asked about the reason for this she responded,

School, because of the school. They only give him one meal.... The other time is spent in activities with other kids. They would have to pull him out and put him in a quiet room or so, to feed. And I want him to be with the other kids, because they start stretching on the floor, doing this, doing that. So you can't have a g-tube dangling all over the place. So you can't have him sitting all the time, watching the rest. Well he seems to be coping very well with that.
Her decision to move Tim to a feeding schedule that more closely simulated a traditional meal pattern, allowed some sense of normalcy around his feeding, if only by ensuring that he could participate in activities with his peers as opposed to being fed constantly. Indeed, this helps us understand the significance of bolus feeding for families, since this practice can more easily simulate normal mealtime patterns. Melissa, whose son was more mobile, installed hooks all over her home so that Joshua could have maximum flexibility in terms of where he was fed. "This way he doesn't have to stop what he's doing every time he gets a feed". Rather than trying to normalize the feeding environment, both these mothers attempt to ensure that feeding does not encroach on the other activities in their children's life. In this way they place limits on how far away their children's tube feeding can move them from the norm.

7.2.3 Creating a normal relationship to food

Food is a way to teach children developmental concepts such as taste and texture. There are few natural opportunities to teach children these concepts when they cannot eat by mouth. Some parents grappled with the dilemma of wanting their children to learn about and experience different tastes or foods in the face of the danger of eating. During an observation with Joshua, Melissa asked if I would give him a taste of my cranberry juice. She used the opportunity to talk about the concept of sour food. Similarly Cassandra allowed Star to have some chocolate cake her sister had ordered at a restaurant. The cake was used as a tool to talk about sweetness and the decadence we culturally associate with chocolate. Lindsay and Joshua, who were the two most cognitively advanced children in the group, also had the chance to learn about choices with food. During observations, both children had the chance to buy a snack from the cafeteria vending machine. Joshua chose a chocolate bar for his mother, spending fifteen minutes having me recite the possible selections to him, placing the money in the machine and pushing the appropriate
buttons. This kind of activity was indicative of an effort to include children in a number of non-eating activities around food. Another example was children's participation in meal preparation. Parents had them hold bowls, guided their hand as they stirred foods or simply placed them in the door of the kitchen so they could watch the room's activities. Carolyn describes this involvement in her family.

We lie (Wilson) on the counter when my husband cooks, part of it is water from the sink and he watches the chopping. I don't know if he knows that that's cooking. He bakes. You know we sit him in his chair and he stirs stuff. So he's participating in activities that are around food, maybe not as much as a normal child would, even though he's not eating.

Although these experiences are associated with themes of progress and development, they are also attempts to "normalize" the children's experiences. In part, children's participation in food selection, purchases and preparation was an effort to integrate children socially. Parents recognized the enormous social dimension of food and eating and their child's risk of social isolation if they could not participate in these activities. Probably where this was most striking for parents was with respect to social occasions that centered around food, such as birthday parties.

Children's birthday parties presented a special challenge for parents and possibly the children themselves. Many parents brought up these events in the interview, mentioning their uncertainty about how to handle the event appropriately. Most opted to keep their child's participation as close to what other children were doing as possible. Children were seated with other children when the food was served and they, like everyone else, were given a plate with food on it. The children in this study were often encouraged to have a taste, to smell, to touch and to play with their food. Melissa described her worry in planning a party for her own son.

Well the first birthday after the g-tube was put in was really worrisome. I fretted over whether I should have a cake or not. You know that's really the central focus of the party, blowing out the candles on the
cake. And what would it mean to Josh if we didn't have one. Well then it turned out like this. Josh really loves knights and dragons and castles and all of that. So he chose that theme for his party. Everyone was dressed up like a knight and he was a dragon. You know the decorations and everything. And then he asked for a castle cake. So that decided it. I got a castle cake made and we sat around and he blew out the candles. Everyone got a piece, including Josh. And I thought, okay he can have a taste, it's just one day. But he just wanted it on his plate and that was it - he didn't even touch it.

The manner in which Melissa arrived at her decision about the cake was unique, since Joshua was able to communicate his preferences. Other parents faced similar concerns, but did not have as strong cues from their children as to what course of action to take. In the absence of this overt guidance, parents opted to follow established norms. This however did not always resolve their anxieties as Carolyn indicates.

He's not necessarily in an integrated feeding environment (at school). And I don't know if it is appropriate for him to see all the kids eating they're low down and he's not. It may point out that I'm more different than the other kids.

7.2.4 Limitations

Keeping children's mealtimes as normal as possible helped minimize some differences, however they cannot be eliminated entirely. Eventually parents confront the limitations of this approach. As Carolyn describes, trying to minimize the differences can heighten how different children actually are. The popularly accepted goal of having integrated classrooms means that the degree of difference between one's child and his or her classmates is brought into relief.

It is critical to note that more families may have chosen to keep things as normal as possible in their children's meals, but were impeded by structural constraints. For example, Ruth mentioned wanting Sam to eat at the table with everyone else, but the physical layout of their apartment made this impossible. Ruth and her two
teenagers lived in one of the smallest homes as compared to any other family in the study. Ruth explained that it was one of the few accessible units available in subsidized housing and had probably been designed for a single adult. When Sam was being fed, his wheelchair with the T-bar attachment took up almost all the available space in the living room. The frequent spasms associated with his disability made it too difficult for him to join his mother and sister at their dinner table. The space was so small that when his body extended, his feet would hit the table and collapse it. Another issue around the mealtime environment itself was the concern parents had with respect to breakfasts. As mentioned earlier, because children were not able to be g-tube fed at their schools, families had to start morning feeds quite early. Consequently, children were fed in bed or while sleeping, making it impossible to view the morning feeding as a meal. Just as some activities could challenge the construction of g-tube feeding as a purely clinical or unnatural event, this activity reinforced it. This is particularly clear when we consider that often the only time we eat in bed is when we are ill. Feeding a child breakfast in bed heightens their status as "not well". This practice also mimics institutional activities. As families encounter limits to the extent to which they can subdue or minimize differences in their children mealtimes, they experience marginalization once again. Faced with the difficulty of achieving a sense of normalcy in the present, families cast their sights on the future.

7.3 Hoping for a better future
This strategy brings together the notions of parental hope, the imperative of progress or "cure", and the ideal of a norm for eating. The strategy views difference as temporary.

Parents in the study often discussed their children's use of a g-tube within a the broader context of their disability. Generally, there was an awareness of the child's
delayed development, prior to the recognition of the extent of the feeding impairment. As other developmental problems, including the feeding impairment, became apparent, parents began to struggle with the ideas of normality as they related to their children.

(You know you've had a kid now for six months. And everyone knows how kids go through stages. And people see the kid and he remains at a particular size. He is not walking and he is not talking. They get curious and they ask questions and it makes you feel so weird. At first you refuse to tell them. But over a period of time you realize that you have to confront the truth. It's reality, so you can't run away from it. So you say okay so he's got problems, he's got cerebral palsy, so that means he's sustained brain damage during his birthing delivery, and as a result, he can't do things that a normal kid would do.

Over time this parent learned to recognize his son's failure to progress through expected developmental stages as an indication that he was "not normal". While this appears to be an acceptance of the child's disability, this parent, like others in the study, was pulled back into the traditional discourse of child development. The child's disability may become the norm for the family, but there is no attempt to have others view the child's disability similarly. Instead families sought to change their individual norms. Families become invested in their child's progress towards the more widely held norms of progress. As Patricia suggests, "Since (Tim) is getting older we would like him to progress a little bit more towards the norm". Tim Sr. articulates one way in which this could occur: "We would like to wean him off the g-tube and get him feeding like a normal kid".

This last statement captures two important notions. First, the use of the word "wean", commonly used in discussions of breastfeeding, reflects how g-tube feeding may be perceived as an "immature" practice, one which children will "grow out of". It also reflects how hope for a better future is connected to overcoming the implications of g-tube insertion. Families perceived a number of shortcomings with g-tube feeding, which were most evident in their accounts of the decision to insert a
g-tube in their child. The greatest point of similarity among the families in this study was their ambivalent reaction to the suggestion that their child be fed by g-tube. A number of other studies have explored this process (Guerriere, 1998; Spalding, 1992) with similar findings. Parents recounted reactions of fear, anger, sadness and guilt surrounding the time they had to first consider inserting a g-tube in their child. Feelings of betrayal and anger were clearly directed towards the medical practitioners who made the initial recommendation for a g-tube.

7.3.1 The threat to hope

Families identified the physician's recommendation to insert a g-tube into their child as divestment of responsibility. Mothers used "gave up", "copped out", "didn't try hard enough" to describe the physician's advice to stop feeding by mouth and begin g-tube feeding. There was a belief that more could have been done to maintain oral feeding in their children. Families often stated in both the clinic setting and the study, that the doctor's decision to institute enteral feeding was based on an evaluation when their child could not be expected to perform better.

Well she showed aspiration when they did the video (barium) swallow test. But then I told them she had a cold and wouldn't that affect the results? And he said "Oh you should of told me she had a cold." You see children have more trouble with swallowing when they're sick. But they didn't redo the test until some time later.

Parents would try to explain to clinic members that exceptional circumstances led to the appearance of aspiration on the barium swallow. They maintained that their child was sick or tired that day, that under better circumstances, he or she would be able to eat without aspirating. Families also expressed frustration over the fact that their child was only evaluated once. They believed that their child had probably progressed since their initial study. For their part, feeding clinic staff acknowledged to families that they might be correct, there may in fact be times when their child did not aspirate. However, one incident of aspiration was all that was required to put a
child at risk. Children had both good and bad days in terms of eating, and it was the bad days that were cause for concern.

Parents believed that their child's use of a g-tube was temporary. At minimum, they hoped it would someday play a smaller role in providing their children with an adequate intake. There was a strong motivation to move children off the tube or at least lessen their reliance on it. Even, Roberta, who was reluctant to remove the g-tube completely from her son Gary, outlined how she made sure that Gary continued to eat by mouth when he was first put on the g-tube. She, like almost all the mothers, was concerned that the g-tube would become the sole means by which her son received food.

In part the belief that g-tube use would be temporary arises from parents' misunderstanding of the chronicity of their child's condition. For example, several children in the study were using g-tubes as the result of aspiration. Families understood that their child's lungs were being damaged by the aspiration of food, but tended to view the problem as temporary.

We thought naively that Wilson's lungs would heal like a cold like "let's wait a week or two and then take an x-ray. You know his lungs will return back to normal". Things will resolve and maybe get him a little stronger....That strength would somehow manifest itself in an ability to eat safely.

Often, the feeding specialist was first alerted to the presence of aspiration because children experienced repeated respiratory infections. Since parents have few references for chronic respiratory damage related to aspiration, it is not surprising that they would assume that rules of recovery for "normal" children would apply to their own. Parents heard that aspiration led to lung damage, assumed that this damage could be repaired, and the g-tube could be removed. At first it seemed difficult for parents to step back and see their child's impairment being at the root of the aspiration and consequently the reason for the g-tube use. Just as researchers
have noted in other studies (e.g. Charmaz, 1990), the implications of a chronic condition seemed difficult for these parents to grasp. As well, g-tube use in this population is relatively new, and no estimate of the ideal length of its use seems to be offered in the literature. Even in the clinical setting, the feeding assessment team was reluctant to speculate on how long a child would need to be fed via g-tube, or that its use might be indefinite. Although no one confirmed the assumption that g-tube use was temporary, at no point was it ever explicitly denied.

The g-tube insertion also represents an unwelcome nutritional intervention, which, as discussed, signals the extent of children’s disability. This alone would be enough to understand why parents react so poorly to its insertion. However the sense of betrayal parents express illuminates another symbolic dimension of g-tube use. It is assumed that medical interventions will resolve a physiologic problem (Benner, 1987). As outlined in the review of literature, the nutrition community regards gastrostomy feeding as an efficacious means of resolving the problem of children’s undernutrition and aspiration. Parents, on the other hand, have a much larger definition of their children’s problem. As we have seen, their children’s deviation from norms with respect to eating and community participation, in addition to their delayed and curtailed growth and development, form the basis of parental definitions of the "problem". Gastrostomy feeding then can never be accepted as a means of achieving children’s well-being, since it contributes to their social division from peers. Parents might have been able to accept the g-tube temporarily, but as a long-term intervention, it represented the medical community’s abandonment of their children. Isolated in caring for their children, parents struggled to continue the work of resolving their children’s problem and moving them to what they believed represented the best possible outcome.
The desire for the "best possible outcome" was evident as parents persevered in their efforts to "keep the oral going". Parents were concerned that children would lose their ability to eat by mouth if they were to rely solely on the g-tube. Oral feeding, even when strictly sanctioned by doctors was a way to keep the door open for eventually eating by mouth again. Closely tied to this, was the idea that children would eventually progress developmentally in other ways. Although g-tube feeding produced observable developmental and physical progress in children, families felt that this progress could only be maintained if their children ate by mouth. Under some circumstances it was quite easy to follow parents’ thinking. Ruth, for example saw feeding her son certain textures as helpful in his progress towards better oral motor skills.

You can work with the puree. Now I find he can swallow a little more. We can work with the purees and see what happens, right?

Mary, Lindsay's mother, also makes the link between progress and the practice of oral feeding.

I thought the goal of eating and being on a g-tube was to not be on a g-tube any more. That's the traditional goal. For a couple of years, Lindsay wouldn't be using it.

Mary was so invested in this goal of progress that she did succeed in getting her daughter off the g-tube. Unfortunately her nutritional status became compromised, worsening her primary condition. At the time of the study, Lindsay, an eight year old, weighed 10 kilograms, her highest weight ever.

Other parents appeared more invested in the idea of progress in general. Rayna's and Gary's parents believed that eating by mouth established their children's ability to begin talking. Although this may be a logical assumption, families were frequently informed that this was not the case in their visits to the feeding clinic.
Eating by mouth also provides both the child and parents with the opportunity to explore likes and dislikes around foods and particular tastes. Ruth’s comments, illustrate how her son Sam was able to demonstrate growing skills and maturity in his evolving eating habits.

Now when he was small he would spit the carrots out and we thought "Oh he wouldn’t like the carrots." But he likes the carrots. He likes peas now, that he wouldn’t eat when he was small.

Both these foods tend to be preferred by adults rather than children (Satter, 1991; Lambert-Lagace, 1982). Therefore even small tastes given to children could signify their ongoing growth and development.

Parents became invested in the idea of progress based on the improvement in their lives as a result of progress to date.

Well it’s moving forward from where you couldn’t touch Rayna like this. You couldn’t touch her mouth at all, she’d fight you off. To now where I’ve personally fed Rayna in one feeding, an entire Farley cookie, mixed with milk and fruit. And she’s gone from zero ability to swallow to that point now. And it’s been a continuous progress. So we see, down the road, that Rayna will be able to eat some more orally. Now whether we can rid her of this pump completely only time will tell.

There is a great deal of developmental progress involved in moving a child from oral hypersensitivity to the point that they can handle a soft puree like a Farley biscuit. Although the speed along which Rayna travels this developmental trajectory is a much slower rate than her peers, at least the path is similar. The fact that her progress has been continuous gives her father hope that this will remain the case. In this passage he is cautious about the final outcome of his daughter’s progress, but it seems likely he would prefer to "get her off the pump completely".

Even if parents had not seen the degree or rate of developmental progress that they might have wished, they still were able to find sources of hope.
We have the comfort in knowing that the kids don't usually progress until age five and up. You don't see any significant progress until then. At least in the initial years. Maybe after five or six. A lot of what you hear is that the kids start talking after five or six, start walking after five or six. So we have a future to look forward to.

Although this passage does not deal specifically with eating skills, it captures the sense of hope many parents have for their future. Their child still has time to improve, to develop to the point where he can carry out the same activities as other children. As Gary's mother speculated about his ability to eat a wider variety of foods,

Well you know these things take a while, but I think he has the capability. Maybe a different level. He has it all there, but his body is just not co-operating with his brain.

Again this comment illustrates that families are future oriented in their trust and hope in the potential of children to overcome their physical impairments.

Eating by mouth and oral feeding became symbolic of families' hope. Other studies have pointed out that for many families the insertion of the g-tube often was perceived by parents as the loss of the last normal or "fully human" activity their child could perform (Brotherson et al, 1997; Spalding, 1992). Similar themes were seen in among the comments made by the parents in this study. For example.

Yeah, she was delayed, still she is delayed because she is not eating orally like a normal child. She is eating orally a little bit, but not like a normal child.

If normal children eat orally, then the promise of normalcy for one's child rests with his or her ability to eat orally. Parents' concern for their child's progression towards oral feeding then, was in essence their hope for a more normal future.

Oral feeding holds a promise of not only being able to view one's child as normal, but also being normal as a family, as Adriana and Steve's comments exemplify.
We're a little bit more mobile now than we used to be. And now that Rayna is able to eat much more orally, we can see where it's going. We can go on little excursions and give her some food orally.

Adriana also was looking forward to being able to attend her brother's wedding. Her expectation was based on the assumption that Rayna would continue to eat, improve her oral feeding skills, and not have to be pump fed during the wedding. Given the extremely awkward manner in which Rayna had to be pump fed, lying on a reclining adult, and her excessive reflux, oral feeding was an attractive option. In light of difficulties that this family experienced in terms of getting someone to baby-sit their daughter, their only hope for a normal life, or at least social life, was to get Rayna to eat by mouth.

7.3.3 Maintaining hope
There were a number of consequences of hoping for a better or more normal future on the children's meals and mealtimes and feeding. They centered around keeping the doors open for children to eat by mouth. In particular, parents focused on maintaining oral feeding skills and keeping their child's body ready for food. This practice may have been encouraged by the use of the word "delay" by the medical community when referring to children's impairments. To be "delayed" implies that physiologic and cognitive normalcy will one day arrive.

The inclusion of oral feeding at any cost, was the most obvious manner in which the hope for a better, more normal future manifested itself in children's feeding. There were many examples of the lengths families would go to "keep the oral going".

It's a battle. I'm not sure if it's different for all kids with feeding problems, based on fear from the person who is doing the oral feed, administering the food. Like you say all kids are different and some are difficult, you have to be fearful and fearless at the same time....If the child is able to eat orally, not to accept the g-tube. To push the oral
feeding and be aggressive. As a parent that is probably hard to push your child. We did it in a very structured way.

If a parent cannot accept the g-tube as permanent, then there is a strong drive to get their child off, as mentioned above. This desire is put into practice as "aggressive" feeding. While parents seem to draw a line at force feeding, it was not clear from observations, what this distinction was based on. Practices around oral feeding often appeared to cause distress to the child, hardly creating a "normal" mealtime situation. One can assume that given the investment in progress, especially in light of the positive progress their children may have already made, that parents hoped the oral feeding interaction would become more normal in the future. This raises questions about how the imperative for progress and normality in the future affect the children in the present.

When parents were not trying to keep children's oral skills going, they focused on maintaining the readiness of their child's body for food. The frequent incidence of reflux left families aware that their child's GI tract had to be maintained. This desire to keep the body working in preparation for oral feeding was evident in Patricia's refusal to insert a gj-tube in her son.

I wanted the stomach to work, because that's what the stomach is used for. Because, I tell you what. I saw this little girl in (Hospital), she had a gj-tube. Her mom tried to feed her and that bottle was just peeing out of her mouth, green as grass, and there was projectile vomiting over the wall, I said no way, I don't care what they say, they would have to put me in prison...He has a stomach, the stomach is operating, use it. Because if you don't use it, it's going to shrink and then where's that bottle going to go. It's got to come up or something.

In Patricia's view, atrophy of the stomach muscles that might occur from disuse would eventually eliminate the possibility of ever using the GI tract normally again. This might also explain the use of bolus feeding, since parents might believe it would maintain the GI tract's ability to handle the amount of food usually eaten in a meal.
Another way in which families maintained the readiness of their children's bodies was by using the homemade formulas through the g-tube. Families perceive the homemade formulas as enhancing their children's health.

I've been doing it (using pureed foods through the g-tube) since Tim was able to take solids. It didn't kill him or he didn't bring back up through the tube or take away from them. I think it added to him. He's very strong.

Tim's strength implies he may one day be well enough to eat by mouth again. Since commercial formulas could be constructed as potentially harmful to children, feeding one's child pureed formula ensured their health and well being, and perhaps ultimately their prognosis, and with that their potential for normalcy.

7.4 Viewing difference as normal

Well if children come into the world needing support, maybe the kind of support they need, they need it all their life, instead of trying to say well they should try being normal. And maybe their normal is tube feeding every day.

Although all parents made comments like this, this strategy tended to be articulated most rarely. The concept of what constitutes normalcy can be fluid for parents. As dominant definitions of what is normal fail to apply to their children, parents learn to construct their own. One strategy parents could take was to argue that their children's difference with respect to eating and mealtimes was normal. Parents contended that difference between children was the norm.

Melissa's comments tended to capture the essence of this approach

Every child is different you know. I try to see it this way. Children have all kinds of problems with their feeding. For example, some kids have allergies, other kids have very particular tastes, some have religious observances. So I see Josh using a g-tube as the same thing.
This just is the way he eats, and yes it's different, but everybody is different.

As Melissa's comments demonstrate, difference exists within a continuum of what it means to be "normal". Any child, including her own, could be located on this continuum and still be considered normal.

As part of this strategy, parents ally themselves with other marginalized families. The notion of what constitutes a normal mealtime is challenged by pointing out how difficult it is for many to achieve.

Most families aren't normal anyway....(T)here isn't that normal structure of you know parents sitting and the kids sitting beside them eating. We don't have that. I think that's the disadvantage. But nowadays, single parents, there are single parents, there are so many different, you know healthy families out there. And we're just one of those different families. I don't think it's unhealthy...

Mothers took aspects of other children's feeding that could be construed as straying from a norm and suggesting that it also was "differently normal". Everybody can find themselves in the position of being marginalized. Parents use this to create "solidarity" in this marginalized position. In turn they attempt to introduce a different means by which to evaluate normalcy.

Meals and eating tended to be a more open experience for families that held this view. Mothers spent much more time in interviews discussing how their children socialized with others during occasions that involved food. This is evident in Carolyn's comments.

(I)f we go to a party and people don't know us so well, they go "what's wrong with him, doesn't he talk, doesn't he this and what are you doing with him and that tube?" and we go "Hey look at this!" Lift up his shirt and go "Look! This is a tube that goes right into his tummy. He can eat faster than you. Yours has to go down here."
Viewing children's g-tube use as differently normal not only involves constructing the g-tube use as "normal" but also means that others must view the g-tube similarly. Families explain the use of the g-tube to others, carefully outlining why their child needs it and the advantages it can offer. Carolyn and Melissa, who were most explicit about using this strategy, took pains to involve others in the discussions, actively creating a different discourse around normal eating. One way in which they did this was to show their sons' peers the feeding pump, "normalizing" it by making it more familiar and commonplace. Mothers also tried to ask for input in decisions concerning the g-tube use, just as any other mother might for problems that she faced in raising her child.

Families developed this strategy, in part as a reaction to others. Melissa's story of how she explained the fact that Joshua did not eat by mouth clearly illustrated this.

Once we were actually at a clinic in an office. Yeah not in the hospital, but at an office. Um, I was talking to someone and this mother of two older boys...everyone was getting a glass of water and the mother asked if Joshua would like a glass of water. and he said no, it goes to my lungs. And she said "Oh I'm sorry" and "how terrible." And I said, "Oh not terrible, he has a g-tube. It's not terrible."...you know "Oh poor Josh." No, no. You know that's what I'm trying to promote with him. It's not a big deal you know. It's different, everybody's different. This is how you eat. No big deal.

Melissa's assertion that Joshua is "just like everyone else" comes in reaction to pity from the other mother. Similarly, Carolyn frames Wilson as simply "different like everyone else", in reaction to questions about what was "wrong" with him. One might view the parents' reaction in these contexts as denial of the extent of their children's disability, however it would be difficult in these cases to do so. First, difference is acknowledged. Mothers simply try to remove the negative value from the difference, claiming it is "not terrible", "it isn't unhealthy", and sometimes, as for Wilson at the birthday party, it can even be an improvement over other children. As well, other comments by families dismiss the possibility that this
strategy reflects denial. Parents who used this strategy spoke at length of their need to come to terms with their child’s feeding impairment and the struggles that they still faced or feared in the future. Rather than denying their child’s feeding impairment, mothers attempted to actively offer an alternate reading of it.
This final chapter summarizes the findings and discussion presented in the previous four chapters, and introduces their implications. The implications have been divided into three sections: implications for family, implications for theory, and implications for professional practice. The division of implications into these three sections is often arbitrary; certain points may have relevance to all three areas, but have been placed under the heading I felt was most appropriate. The Chapter ends with a critical reflection about the research process.

8.1 Summary of findings
The purpose of this study was to explore the mealtime and feeding context of children who are fed via gastrostomy. Observations with children and interviews with parents provided insight into the mealtimes and feeding environments of eight children with neurodevelopmental impairments. Although mealtimes and feeding practices varied within the group, as well as for each child individually, similar themes were evident throughout all the observations and interviews.

Families carried out the work of caring for their children, including the work of feeding, in a context that held strong discourses of what constituted appropriate care, but provided few consistent supports. The families in this study were determined to raise their children in their own homes. Family based long term care was perceived as being crucial in providing children with "as normal a life as possible". However, with the initiation of g-tube feeding, parents found it almost impossible for their children to participate easily or fully in the community.

Although all the children in this study had significant physical and cognitive impairments, the insertion of a g-tube changed their needs in a manner which
could not be easily or adequately addressed by the community. Schools were reluctant to take on children's specialized needs. Extended family and friends sometimes withdrew from the family, uncomfortable with children's level of impairment. Even friends and relatives who were willing to provide support, could lack the skills and capacity to do so in a consistent, meaningful way. Families could not even use community services such as a local emergency room once a child began using a g-tube.

Parents repeatedly tried to access services and resources which were designed to help them care for their children in the community. However, it was difficult to obtain information about these services; families could not always find out about the existence of needed services. Once services were located, families often found that they did not fit the qualifying criteria; in spite of their increased and specialized needs arising from caring for a technology dependent child, families were apparently not in enough need. In the effort to accommodate themselves to institutional limitations, parents tried to consolidate whatever personal resources they possessed. There were limitless possibilities of what families could invest in the effort to care for children at home. Mothers gave up sleep, leisure time, career or career opportunities and their future financial security. Both parents abandoned plans for the future, traveling, social life and sometimes extending their family. Even siblings lost some of the carefree aspects of childhood, taking on some of the adult responsibility of caregiving.

A closer examination of the social and economic context of each family revealed that in order to keep their child at home, families made sacrifices that often leave them marginalized relative to their peers. These sacrifices were often the result of the challenges families face in trying to provide home based long-term care to their children. The irony is striking. Families choose to care for their children at home
so they can be "normal". Caring for children at home puts a family in the position where they are constantly confronted with the fact that their child is "not normal". At the same time, families themselves moved further away from community norms. With the failure of structures to help families become integrated into the community, families constructed their own strategies for inclusion and integration. One of the major ways in which families did this was to reconstruct their children's meals and feeding.

Mealtimes were constructed at a high cost to families. Feeding practices often led to an increased burden of care for parents, as they invested time, family living space, and energy to accommodate complex mealtime preparations. Members of the health care community perceived some of these practices with concern since they may have led to questionable health outcomes for the children. These and other concerns were warranted, as children sometimes, as with oral feeding or certain methods of bolus feeding, demonstrated both discomfort and distress. In spite of this, families viewed their practices as integral to the care of their children. Parents repeatedly suggested that other families would benefit from knowledge about these feeding practices. Parents actually "redesigned" this study in order to describe these practices as a critical part of caring for a child with a g-tube. To accept the g-tube unproblematically is tantamount to accepting that one's child will always be different, will never progress, will never participate in their community. If their child will never be able to participate as a mature, full member of the social order (Lupton, 1996; Mayall, 1998), parents will have failed in their responsibility to "raise" their child.

To a limited degree, mealtimes were constructed to accommodate the reality of each child's feeding impairment. However, mealtime constructions appeared to be primarily a reaction to their marginalization produced by governmental policies.
The decisions families made about feeding their children reflected their efforts to fit their children into discourses of normalcy and health. In order to accomplish this, parents took advantage of the symbolic and social meanings of food and eating.

Parents perceived what might have appeared to be even the most material aspects of their children's feeding, as drenched in symbolic and social significance. Unlike Marjorie DeVault's (1991) study, where mothers' work of feeding their family was largely invisible and taken for granted, the parents in this study explicitly and reflexively constructed their children's mealtimes. Parents strove to engage in practices which would confer normalcy on their children. When this was not possible, they engaged in practices which would minimize their children's difference. A practice such as feeding children by mouth provided some benefits such as helping children experience tastes, and sensitizing their mouth, however it also carried risks for children. Yet parents integrated oral feeding into their feeding practices whenever possible. Feeding by mouth was symbolic of the possible resolution of their children's feeding impairment, their children's potential for progress and their children's improved developmental status. Oral feeding diminished the social differences between children and their peers, enabling them to participate in social occasions, engage in the commensual act of sharing the same food, or even sit at the mealtime table. In this way the practices which comprised mealtime constructions, gave families, and perhaps even the children themselves, the chance to move closer to social norms.

8.2 Implications for the family
There are three major implications that arise for families out of this study. The first is how parents' caring work for their children was focused around negotiating the difference between the lives of their children and social norms. The second deals with how, despite the advent of deinstitutionalization, children and their families
remain segregated. The final section deals with the implications for children's voice and its "absence" in much of the study.

8.2.1 Re-defining difference

Other studies have noted that parents of children with disabilities struggle to create normalcy in their lives (Davis, 1963; Birenbaum, 1970; Voysey, 1975). Parents in each of these studies attempted to deal with the differences brought about by their child's disability by defining discrepancies in their children's or their own lives as normal occurrences. Delayed development, for example, was redefined, not as a problem of the disabled child, but a "misperception" brought about by comparisons with siblings, relatives or friends who were developmentally precocious (e.g. Birenbaum, 1970; Voysey, 1975). These studies focused on daily family life, examining parents' actions and interpretations in what might loosely be termed "impression management". Davis (1963) studied the families of children who had physical impairments as the result of poliomyelitis. Families engaged in processes of normalization, where they sought the validation from others who supported their definitions of their child's normalcy. They practiced disassociation from those who did not support their definitions, thereby maintaining the normalcy of their children and themselves as parents. Birenbaum (1970) also demonstrated how parents of children with cognitive impairments attempted to maintain definitions of their children as normal. Her analysis, however, focused on how families managed "courtesy stigma". Those who experience courtesy stigma act as "models of normalization", demonstrating to others how the stigmatized should be treated. Birenbaum, like Davis and Voysey, demonstrates how parents strive to manage the perceptions of others, creating an environment where their children can be seen as normal. In turn, this may alleviate parents' own stigma, since if others perceive their children as normal, this will attest to parents' ability to maintain conventional family life.
Voysey (1975) also studied the families of children with a variety of disabilities, focusing on the context of "relevancies" or common sense understandings of moral definitions of normal children, families and parenting. Parents sought to define the discrepancy between their children's expected and actual behaviour and appearance in ways, that while "congruent with the limitations imposed by medical definitions" (125), could fit within themes of normal child development. Voysey's analysis parallels the findings in this study in several respects. Families engage in strategies to reconstruct the meaning of their children's disability. They also try to impose order on their children's behaviours, much like the efforts of the parent of g-tube fed children to "subdue" and "control" their children's bodies. In both studies, paradoxically, these efforts often involve emphasizing the extent of children's difference in order to obtain needed assistance from others.

While the parents of children with g-tubes appear to engage in similar activities of normalization and impression management, as the parent above, there are some differences. The practices, in the studies discussed above, reflected a parental concern to ensure the normalcy of their children, much like the mealtime practices of parents in this study. However, the previous authors were not concerned about how these practices contributed to the context of daily life for the child. Greater emphasis was placed on the parents' interpretation of the child's disability and issues of both the families' and their children's identities, rather than how the actions arising from these interpretations might contribute to the child's well-being. A second difference, is that these authors paid little attention to the structural environment in which families lived. Parents redefined the difference arising from their children's disability in relation to meanings others held regarding normal child development and normal parenting. Similarly, parents of children with g-tubes attended to the "discursive environment" which encompasses the meanings,
beliefs and attitudes of others. However, there is an acknowledgment, in the findings of this study, that one of the major ways in which families come to understand the need to reconstruct their children's difference is through interactions with institutions. The relationship between their child's disability and difference, and structural constraints figures much more prominently in parental understanding of their family's social location. For the parents of children with g-tubes, difference not only needs to be redefined, difference is also imposed by institutions. The lack of emphasis on these constraints in earlier studies may reflect a difference in theoretical orientation. However they may also reflect the historical context in which the studies were conducted. Each of the previous studies was carried out prior to the social movement of de-institutionalization; therefore parents who took part may have possessed greater resources, both financial and social, which enabled them to raise their children at home. These families may have been less likely to experience the same constraints as a more representative, current-day sample of parents of children with disabilities.

8.2.2 Implications for family based long term care

Although families were strongly committed to the ideals of deinstitutionalization, it often seemed as if children continued to be institutionalized, but within their own homes. Where children were once institutionalized geographically - by being housed together separately from the rest of the community, the children (along with their families) now were "institutionalized" through the policies of various social institutions around them.

One of the major consequences of institutionalization is that "deviant" or unwanted individuals are confined away from the general community or encouraged to be "normal" in order to be reintegrated (Goffman, 1961). The community integration of people with mental illness illustrates how
institutionalization can continue outside the walls of a building. Psychotropic drugs have been viewed by some as a means to continue confining certain disruptive or unwanted individuals from the larger community, creating "an institution without walls" (Schwartz, 1992; CILT, 1995).

While the situation seems far less intentional with the families in this study, several institutionalized practices and policies appear to confine them separately from their peers. Scott, (1969) in his study The Making of A Blind Man, outlines how institutional practices shape the way individuals live their lives. He notes that visually impaired individuals can have marginal vision for a great length of time and simply be considered as persons who "have trouble seeing". As soon as individuals are officially declared to be "legally blind" they enter a new role as "blind persons". They no longer belong to the world of the sighted. Integration is no longer achievable when one has this disability; "blind men" are destined to roles on the margins of society. Dependence on a g-tube appears to serve a similar function for children. When children are fed solely formula through a g-tube, their difference is heightened, and their integration into the community cannot be easily achieved.

8.2.3 Implications for children's voice
Several authors, including Lupton (1996), James (1994) and Satter (1990), contend that the feeding experience for children provides opportunities for autonomy, control and meaning. The feeding experience for the children in this study rarely afforded the same opportunities, at least while parents are trying to actively enact the discourses which surround them. Mealtime constructions appeared to be imposed upon children, in the same manner that the need to develop these constructions was imposed upon parents.
Murphy (1987), as he wrote in his autobiography, found that his paralysis rendered him increasingly silent, as his capacity for non-verbal communication through gesture, stance and bodily proximity became impossible. Without verbal communication ability, the children in this study also became effectively "silent". However unlike Murphy, these children often could communicate corporeally: crying, laughing, becoming angry, physically twisting themselves away from adults, spitting out their food, refusing to open their mouths. In spite of this, they had no "voice", since their actions and reactions often only became the focus of adult attention when they fit the discourse of normal child development. Parents "listened" when children expressed an interest in food, reacted positively to a particular taste or demonstrated a new physical ability.

In part, children's silence reflects their status as children and therefore as members of a socially marginalized group (Mayall, 1998; Solberg, 1996). Age and functioning of the physical body continue to be used as a dominant classifying principle within childhood (Alanen, 1992). Children's passage to maturity is marked through stages of bodily achievement and control (Mayall, 1998). Therefore children are seen as "human becomings" (Qvortrup, 1997), unable to express their needs fully or accurately. As such, there is little social incentive for adults to "hear" their children.

Children's silence may also be due to the ways in which adults "read" their bodies. For example, as a society we have established conceptual links between body size, shape and appearance and social identity (Bordo, 1995). For example the slender, muscular body can be "read" by others as a sign of control, discipline, beauty, asceticism or dysfunction on the part of the person who possesses it (Bordo, 1995; Crawford, 1984). O'Neill (1989) suggests that the ways in which we perceive children's bodies and their actions is constrained by the discourse of child development. Classical theories of cognitive development, reflex or learning theory
tend to influence these discourses and influence how we interpret children's actions. Children's drawings are often seen as evidence of their dexterity, attention to detail or cognitive grasp of geometry. This positions children's drawings as a form of imitation of the adult world; it fails to note the picture as an expression of a child’s relation to his or her environment. O’Neill argues that the quality and content of a child’s drawing will change over time, and these changes reflect his or her continually evolving relationship to the world, as well as changes in physical ability and experience. However we tend to attribute changes to the latter. The adults in this study are similarly constrained as they interpret their children’s actions. It may only be possible to interpret children's refusal of food as a sign of their limited physical ability, rather than distress or fear related to past negative experiences. It has been suggested that children may develop physical, perceptual and cognitive skills interwoven with affective and experiential appreciation of their worlds (Mayall, 1996; James, 1994; Burman, 1994). However for the parents in this study, the discourse of normal child development is so strong that it overrides a full consideration of children’s phenomenological experience of mealtimes and eating.

Where parents can react in a number of ways to the discourses surrounding them, it is not clear that children have the same options. Children’s entire context was influenced by social norms of eating and mealtimes. At a broader level, children’s daily context is shaped by able-bodied norms. The practices around children’s care are dictated by the efforts to subdue their difference. Unfortunately, the children in this study will never subdue their bodily difference to any noticeable degree. As long as families continue to accommodate their lives and their children’s bodies to their social and discursive environments, rather than society taking responsibility in changing the environment to accommodate children and their families, children are destined to remain disabled. The presence of their multiple impairments,
coupled with the economic, social and personal constraints imposed upon their families, limits their ability to participate fully in everyday social life.

8.3 Implications for theory

Difference was double edged. It was crucial for families to highlight their difference in order to gain the resources needed to raise their children in the community; they had to fit the classification system that entitled them to certain services. However this process contradicts the imperative all families experience around normalcy and integration. Indeed the process of asking for support based on specialized needs acts as a form of self imposed surveillance. Following the Foucauldian notion of governance, families recognize how marginalized they have become and strive to enact the norms present in their discursive environments.

Foucault (1991) argues that the work of governance is shared between the society, the family and the individual. He conceptualizes the relationship as "triangular", with all three components equally responsible for effective governance. Lupton (1997) argues that this shared responsibility is accompanied by a "diffusion" of power. Governance cannot work if individuals and families do not attend or enact social discourses. I would argue that for the families in this study, it is more appropriate to view the relationship between society, parents and children as "nested". Parents' individual agency is constrained within a web of discourses, many of which are manifested through institutional practices. For example the discourses associated with community integration and de-institutionalization make it impossible for parents to think about raising their children anywhere other than their home. As parents find themselves governed, they, in turn, submit their children to similar constraint. Just as Bordo (1985) has argued that individuals with an eating disorder have crystallized the harmful social notions of thinness and self-control, parental constructions of their children's mealtimes and feeding crystallize
the discourses of normal child development, subjecting children to them. Children's mealtimes reflect a discursive context which discourages differences and promotes normal progress and control.

8.4 Implications for professional practice
The Canadian Pediatric Society (1994) contends that g-tube feeding will enable families to care for their children more easily within the home environment; unfortunately their comments do not address the reality faced by the families in this study. Instead, the initiation of g-tube feeding, designed to resolve the consequences of the children's feeding impairment, introduced new challenges to the family.

The initiation of g-tube feeding among the children in this study reflected one of the major consequences upon clinical practice that stems from the Cartesian conceptualization of the body. This centres around the technological imperative that emerges from viewing the body as a machine (Herzlich, 1995). The Cartesian view privileges efforts to map or "blueprint" the individual components and causal pathways within the body (Leder, 1984; Pronger, 1995). Presumably this produces the knowledge needed to mechanically intervene with the body (Herzlich, 1995). Thus prescriptive approaches are developed which are narrowly focused on correcting "mechanical" anomalies or functional impairments. Other consequences or outcomes are seen to be of little relevance.

Oliver's definitions of disablement brings relevance to these "other consequences". In his book the Politics of Disablement (1992), Oliver identifies the personal tragedy approach as one of the major ways in which we have conceptualized disability. According to Oliver this approach, which defines disability as the result of personal misfortune, has contributed to health policies and practices which are targeted at an individualistic level. Traditional medical interventions are a example of this
definitional approach. Oliver suggests an alternative of viewing disability as located in the social, economic, physical and political environment. This view contends that while individuals may possess certain physical impairments, whether or not those impairments become disabling depends upon whether the environment is able to accommodate them to the extent that the individual can continue to participate in everyday social life. Following this perspective, people with disabilities find their movements limited because of environments which are not designed to be accessible to all. This can be compounded by the fact that many have financial resources too low to "buy" their way around environmental barriers (McMurray, 1987).

Rather than merely correcting a physical anomaly as intended, gastrostomy feeding was affected by and contributed to the environments in which families lived. The potential of gastrostomy feeding to alleviate the challenges associated with children's feeding impairments was limited by structural constraints (e.g. lack of access to homecare). Donahue and McGuire (1995), in their discussion of the political power of health care, suggest that the institutional environment has the ability to "deploy and allocate" resources in such a way as "to render some kinds of behaviour possible, while making others less possible". Parents often found that the initiation of g-tube feeding could bring about some positive changes for their children, such as improved nutritional status and less anxious feeding interactions. However, the use of a g-tube placed children in a more serious category of disability. Their needs became more specialized, requiring a higher level of expert care. Informal caregiving support fell away, as relatives and friends were fearful and uncomfortable about caring for a technology dependent child. More formal caregiving supports were limited, not easily accessible and often demanded that parents "prove" their worthiness. The lack of structurally embedded resources limited the types of activities parents could engage in. Their activities revolved
around restructuring domestic life, ignoring the phenomenological well-being of individual family members.

Kaufert and Locker (1988; 1990) also found that the use of technological interventions was affected by an individual's environment. Individuals with post-polio respiratory disability had to trade off advantages of various forms of ventilation technology with a number of disadvantages. Individuals who wished to use positive pressure machines, a more favourably regarded technology, needed a primary care partner who was both willing and skilled enough to take on the task of assisting with its technological care and maintenance. As Kaufer and Locker point out, only individuals with support networks and resources to obtain skilled help were able to take advantage of the opportunities offered by certain technologies. Others who lacked the resources would be confined to ventilation technologies which made them more passive, restricting their ability to participate in social life. Kaufer and Locker's findings could be applied to the difference between Carolyn and Wilson, and the other families in the study. Equipped with the best set of resources of all the participating families, Carolyn and Wilson were in the best situation to take advantage of what the system had to offer. They also appeared to be able to make the best use of the gastrostomy, since Wilson appeared to be the best nourished of all the children in the study. Other families, with fewer resources, and less access to the system, became more "passive" as their activities became limited to those of accommodating the shortcomings of the institutions around them. Although the use of a g-tube keeps their children alive, its potential as a nutrition intervention is diminished by the fact that structural constraints and social norms prevent families from using it in a way that ensures their children's physical well-being.
Although findings in this study are difficult to generalize to all families of children with feeding impairments, they do illuminate some areas for concern to the nutrition community and social service community in general. As well, they corroborate some of the findings of recent studies (Brotherson et al, 1995; Thorne et al, 1997).

Unfortunately, probably very little could be done to completely alleviate the physical discomfort and reflux so many children in this study experienced. The nature of their central nervous system insult probably contributed to the dysfunction of their gastrointestinal system. However, there are a number of implications for professional practice which can help families, in general, throughout the feeding experience.

The foremost implication is that health care providers need to listen to families. The findings indicate the value in having a conversation with parents and listening to their story. Often the concern, in the nutrition community, is on food and nutrients, measuring the amount and quality of intake. Yet for the families, how mealtimes took place, how feeding occurred, had a far greater significance. A conversation with parents about their concerns and experiences in feeding their children may be a valuable place to begin identifying where parents need support.

The tremendous lengths families took to normalize their children speak to some of their unique education needs. Parents mentioned receiving technical information and education about how to use and maintain a gastrostomy tube with their children. However, parents could also be provided with education regarding the social pressures arising from caring for a child with severe disabilities in the community. Families may benefit from recognizing that others share their concerns regarding the integration and normalization of their children, especially with
respect to feeding. Practitioners may have a role in pointing out some of the shortcomings of the messages implicit in these social pressures for all families. They may also help parents achieve a sense of entitlement and expectation about the support they deserve from society, rather than submitting to it.

There is also a message to the nutrition and medical community to consider how interventions contribute to these social pressures. Even something as seemingly benign as showing families a growth chart can transmit messages of normalcy. Often children's height and weight cannot be plotted on the chart, driving home to parents how different their children are. The activity of plotting children's height and weight on a growth chart also models and reinforces for parents how children can be compared to others. There is a movement within the nutrition community to develop alternate norms for children with disabilities. However the range of disabilities in a condition such as cerebral palsy are so heterogeneous, that it is uncertain whether normative data could be developed. A question for the nutrition community is whether such tools should be developed. Perhaps for a group of children like those in this study, alternate means of evaluating children's well-being must be developed.

Recognizing that some social pressures may be difficult to resist, the findings also speak to the need to help families find ways to mark progress in their children. Typically, children's swallow is assessed, lengthy work is done with the family to convince them of the need for the g-tube, and oral motor therapy is recommended. Unfortunately, for many families who came to the feeding clinic, ongoing community based therapy was difficult to find and continue. Yet parents continue hoping for a resolution to their child's feeding impairment. Consistent access to this type of service may help parents find more appropriate cues to mark their children's progress. Small differences in children's oral motor skills, or perhaps
food related activities that can be achieved in occupational and speech therapy, may help parents discern the progress they seem to be desperately seeking. Health care professionals may have a role in helping parents find ways that measure children's progress and well-being against individualized baselines.

At a policy level, the findings highlight the challenges involved in community integration. Without adequate support to help them truly participate in the community, families turn to individual strategies. Unfortunately, the constraints in their lives leave few strategies possible. While it is difficult to make policy recommendations based on such a small study, some general comments can be made. It appeared that families would benefit if information about resources was more widely available. It also seemed that case managers, who could respond more quickly to families' needs and take on some of the work of locating and securing resources, would alleviate some of the work that currently consumed parents' time and energy. It also seemed that families lacked the financial resources to care for their children alone. The extent to which families had to call on personal support networks and rearrange their lives suggested that it was impossible for parents to "buy" caregiving support. There is a role for practitioners to advocate on behalf of families as they attempt to develop a package of care for their children.

There is a also a need to re-examine school policies regarding the integration of children who are fed via g-tube. Breakfasts were a major concern for all families. It was not always clear why children could not be fed at school, although limited staffing and difficulty integrating a child during feeding were raised as problems at the level of the institution. Yet there would be significant benefits to families if schools could accommodate their needs. Children would benefit as breakfasts could be more social, less clinical experiences, providing them with an opportunity for interaction with other family members or their peers. As well, children may
experience less reflux and discomfort with morning feedings if they were fed sitting up, rather than lying in bed. Given their already tiring schedules, mothers would undoubtedly appreciate not having to get up in the middle of the night to feed their children breakfast.

Many very simple steps could also be taken to alleviate other aspects of the burden of care which parents carried, beginning at the level of the technology. There were many instances when parents had to dedicate time, energy and resources to finding ways to deal with the shortcomings of gastrostomy feeding. Often simple devices, addressing these problems, could have been provided to them along with the feeding equipment. Cassandra could be provided with an effective hook to hang Star's feeding bag in public, rather than using bobby and safety pins, paper clips and elastics as she is now. The wooden board, Melissa was having a friend make to replace the "unsightly" T bar, could be an alternative offered through rehabilitation services to all parents. Parents' practice of syringe bolus feeding may indicate the need to develop more discreet methods of g-tube feeding, rather than relying on the tradition pump and gravity methods. Some equipment, like the portable pump which Carolyn obtained for Wilson, are considered "Cadillac" items and are rented to parents at a premium rate. However, the extra mobility this pump gives parents and their children probably affords them more access into various community and social activities. It is worth considering if this type of pump should be the standard equipment offered to families.

Formulas are another area where changes in professional practice, especially practice based research, may have a positive influence on the mealtime context. As in previous studies (Spalding, 1992; Guerriere, 1998), families used pureed foods to replace formula. In spite of how common this practice is, families believe that they are acting under disapproval from the medical community. The consistency of this
finding suggests a need for a randomized control trial to determine if in fact any concern is warranted, or if families can be encouraged to continue with this practice. Related to this, is that several families paid an extra charge for specialized formulas, such as formulas with fibre added. Often, homemade purees would have been just as effective and far less expensive for families. Given the financial pressures many families experience, practitioners may be of assistance in helping them find more economical alternatives when possible.

In summary, practitioners have a role in bringing children and their families to the table in terms of their care. The experience of families in this study demonstrate how eating is essential for life, both physically and socially. In order to best support families we, as practitioners and researchers, need to introduce and support interventions in a way that address these needs.

8.5 Critical reflection

Several limitations arise in this study, particularly with respect to sampling. The length and need for repeated observation time with participants probably made it impossible for some families to participate. Families had demanding schedules and even those who were eager to participate had difficulty finding a convenient time to meet with me. Recruiting children through the feeding assessment clinic also limited the sample to those participants who "fell under the clinical gaze" (Conrad, 1990). The sample did not capture any children whose families did not attend clinics regularly, who fail to show up for appointments or who are not well connected to the medical system. These families tended to be viewed as more vulnerable or "non compliant" by feeding clinic team members. These families either could not or would not bring themselves to "fit into" the feeding team's definition of good, responsible parents. The analysis in this study would undoubtedly be enriched by the experiences of these families and their children. Another limitation is that the
sample is limited to those families who are fluent in English. Again the opportunity to inform the analysis with the experience of more vulnerable populations is lost. Although two immigrant families are included in the study, it would be interesting to have achieved greater ethnic diversity in the sample. Many non-English speaking, immigrant families were observed in the rehabilitation centre and the feeding assessment clinic. The similarities in concerns and reactions regarding their children’s feeding impairment and gastrostomy use suggests that discourse of normalcy threads through many cultures. Unfortunately, without further study, it is impossible to comment on this.

Any interaction or social situation, including the research situation, is comprised of multiple perspectives. Each player within the social situation has a perspective or an angle of observation and interpretation. In the field, the researcher holds one such perspective, which shapes how he or she views the research problem, the events attended to, and the specific aspects that one pursues and analyzes. The research process can become quite subjective, the researcher telling a particular story about the events he or she witnesses. Alternatively, the researcher’s perspective can become an integral part of the research process, as the researcher records his or her reflections and changes in view over time (Charmaz, 1990; Mays and Pope, 1995). The findings in this study reflect my unique perspective and assumptions. My background and experience with disability, health and illness influence my analytic stance and the manner in which I interpret the data.
9. REFERENCES


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APPENDIX A

Research Protocol

Title: Ethnography of mealtimes of children fed by gastrostomy tube.
Student: Esther Ignagni
Supervisor: Dr. Heather Maclean
Time frame: June 1997 to June 1998
Funding source: Personal funding, Ontario Graduate Scholarship for academic years 1996-97 and 1997-98.
Amount awarded: $12,000 per academic year.

Recent research concerning the implementation of gastrostomy feeding with neurodevelopmentally impaired children provides compelling evidence for its use as a means of preventing and correcting undernutrition\(^1\). However, this research has focused on the biomedical aspects of gastrostomy feeding. While several authors infer that children will experience an improved quality of life with this feeding method, no evidence about the impact of gastrostomy feeding on the lives of these children appears to have been published. This is a significant absence because feeding, eating and mealtimes provide opportunities for children to explore new sensations, assert control and independence, discover preferences, demonstrate growing physical abilities and interact in a social setting. While there is little known about whether these opportunities actually exist for children with feeding impairments, we can have some confidence that feeding represented a guaranteed form of stimulation and interaction. Gastrostomy feeding has the potential to threaten this aspect of children's lives, yet may enhance others.

This study represents an effort to begin to move towards an understanding of the impact of g-tube feeding on quality of life for this group of children. I propose to conduct an ethnographic study that would investigate the contextual issues related to mealtimes in general and gastrostomy feeding in particular. The purpose of this exploratory study is to examine the social environment of mealtimes and the feeding interaction in the day to day lives of children with serious neurodevelopmental impairments who have g-tubes.

**Potential Benefits:**
The findings from this study may be used to plan more focused studies concerning the environment in which gastrostomy feeding and feeding in general takes place. This study has the potential to contribute to a deeper understanding of the daily lives of children with serious disabilities. It may

help dietitians, feeding and nutrition specialists and other health care practitioners better appreciate the role that feeding can play in the lives of these children. Ultimately, this study may help improve interventions aimed at promoting well-being among this group of children.

**Procedures**
In order to determine the role of feeding in the context of their lives, I will ask families to suggest times when I may be able to see feeding interactions in progress. I am hoping that within the sample I will be able to observe children participating in a range of different types of food-centred events (e.g. an ordinary meal, a meal in a restaurant, a picnic). Ideally I will have the opportunity to "track children through several different types of feeding interactions. To this end, I will be asking families if I may observe three separate occasions. I will act as a participant-observer, observing children's activities, behaviours and interactions, recording them in field notes. I will also record the behaviours, actions, interactions and conversations of others in the research setting when the data seems directly related to the children I am studying. More specifically, this will include any data related to feeding, meal and snack times, food and maintenance of gastrostomy. In order to assure that children and other individuals in the research setting are not made to feel uncomfortable, I will record my notes privately. I will take advantage of times when a child might typically want privacy.

**Role of the Researcher**
I will be open about my role in the research setting, clearly stating that I am a student conducting a project on the lives of children with disabilities. While in the setting, I will engage in many of the same activities as the participant. At no time throughout my observation will I engage in any caregiving activities. As well, I will avoid behaving in an authoritative manner, as might other adults in the research setting. I will inform caregivers in the appropriate settings that my role is simply to observe. I will also explain that because I do not want to interfere with normal activities, I will not be able to take on the responsibilities that might normally be expected of another adult.

**Data Collection and Analysis**
Field notes will be transcribed into more formal notes after each day of observation is completed. Data will be analyzed using a constructivist grounded theory method. Data will then be coded according to themes which emerge. Related or similar codes will then be collapsed into larger categories. Categories will be related to one another until a conceptual framework from which we may be better able to understand the lives of this population is formulated.

**Sample**
The sample for this study will be comprised of 10 children between the ages of 6 and 12 years. These children will have a neurodevelopmental impairment that has resulted in the implementation of a gastrostomy tube. Only participant six months post g-tube implementation will be recruited. Because this is a vulnerable population, care will be taken to ensure that both proxy consent and, when possible, assent are obtained.

Recruitment
Study participants will be recruited through the feeding assessment clinics at the Bloorview MacMillan Centre, Humber River Regional Hospital and Doctor's Hospital. Families who are scheduled to visit the clinic will be sent a letter by Dr. Berall describing the study and explaining that I will speak to them further after their appointment. Dr. Berall will then ask them again at the appointment if they wish to meet with me or if he can give me their phone number for me to call them at a later time. If families are willing to meet with me then I will approach them immediately following their visit at the clinic and I will invite their child to participate in my study. If the family expresses an interest I will provide them with the information about the study (see attached). I will offer families the option to either call me back or for me to call them in several days to confirm whether they are still interested and/or willing to participate. If they are still interested, I will meet with them in order to receive formal consent.

The actual details of how observation will take place will be arranged at the time formal consent is obtained. I expect that families will have unique demands and I am prepared to accommodate an observation protocol to whatever these may be. However I will suggest to families that it may be easier to attempt to schedule observation within a shorter time period (e.g. within a month) so that everyone can gain some familiarity with me.

Ethical Considerations

Consent/Assent
Informed assent will be attempted with every participant who is able to communicate in some way. Informed proxy consent will be obtained from the parents or guardians of all participants. When informed assent is not possible, such as when the child has a cognitive impairment or is very young, only informed proxy consent will be obtained. When recruiting study participants, I will explain the consent/assent form and give an opportunity for questions prior to signing. Participants will be informed that taking part in this study is entirely voluntary and that they may stop participating or withdraw from the study at any time. Although participants will be recruited through the Bloorview-MacMillan Centre Humber River Regional Hospital and Doctor's Hospital, their consent or refusal to participate will in no way affect their use of these institutions or other services.
Although my research focus is on the children whose activities I will be following, ethnographic research often involves recording all data in the research setting, including unstructured informal conversations with other individuals present (for example, nursing staff, parents, siblings etc.). Several issues arise from this. Any institution, such as a school, camp or day care setting which the child would normally attend on the day of observation, will be provided with an information sheet in advance and verbal permission of the director or principal will be requested (See attached). If an institution declines permission for me to observe their staff or clients, I will only observe the child in their home or public settings. Individuals in any of the research settings will be informed as to my identity and role. I will also inform them that their names and any identifying information about them and the participating institutions will not be included in the final report.

Risks and Benefits
A risk of discomfort or distress at being observed may be incurred by study participants. If this is noted, observation will cease. In instances where I am not able to communicate with a participant, such as when a participant does not speak or use a communication aid, I will establish guidelines for how to interpret the participant’s behaviour beforehand in consultation with the parent or guardian. If throughout the time of my observation the child appears to wish to be left alone I will leave the research setting promptly and inform the parent or guardian. The parent and participant will decide if and when I will resume my observations.

It is not likely that the study will directly benefit the participants. However it may become evident throughout the course of the research that a participant is at risk. Evidence of physical abuse will be reported to the appropriate legal authorities. Observations of medical risk will be discussed with my supervisor at the Bloorview MacMillan site (Dr. Glen Berall) and then reported to the caregivers, so that they may take appropriate action.

Confidentiality
In order to protect the anonymity of study participants, each will be assigned an identification number at the time of recruitment. They will be referred to by this number in all aspects of data handling. Identifying information will be kept under lock and key in a separate location. Any unique characteristics that could lead to the identification of the participants will not be reported. Examples may include rare diseases or specific details of an accident that led to the disability. Field notes and computer disks will be held in a secure location and only be accessible by myself and the members of my advisory committee. At the end of the study, the list of names with identification numbers will be destroyed. Field notes, computer disks and consent forms will be kept for six years after the project is completed. This in accordance with UTRS policy.
Families and participating institutions will receive a summary of the final data analysis.
Information Sheet for Parent(s) or Guardian(s)

My name is Esther Ignagni and I am a graduate student in the Nutritional Sciences department at the University of Toronto. I am conducting a study under the supervision of Dr. Heather Maclean. The purpose of this study is to describe the daily lives of children have a gastrostomy tube.

I would like to invite your child to participate in my study. This will involve my accompanying your child throughout some of his or her daily activities. I will do this on three separate days that are convenient to both you and your child. I will call you 2 days ahead of each observation day to see if it is still acceptable for me to meet with your child, whether I am meeting with him or her at home or in a long term care setting. You can change any of these arrangements to better suit your needs.

I will not provide any direct care for your child while I am with him or her, but will leave that to people who are normally your child’s caregivers. Because I am interested in how other people interact with your child, it is important that I tell them who I am and what I am doing. I will not take any notes in front of your child or other people, but may take several short breaks in order to do this privately. We will schedule the three observation days when you sign the consent forms.

Everything I see or am told by your child or anyone else will be kept confidential, except in those circumstances where the law requires otherwise, such as suspected child abuse. Your child’s name or any other information that would identify him or her will not appear in any report of this study. Identifying information and field notes will be kept in separate locked locations. When the study has been completed, all identifying information about your child will be destroyed. However I will keep my field notes and computer disks, which will not contain any identifying information about your child for six years.

You and your child are free to ask me to stop my observation at any time, either temporarily or permanently. You are also free to withdraw from the study at any point and ask me not to include any information about your child in my study. Asking me to stop will not affect your service from the Bloorview-MacMillan Centre.

There is a risk that your child may become distressed or uncomfortable about being observed. I will stop my observations if your child indicates he or she is uncomfortable. If your child has difficulty communicating, I will ask you about what I should look for to figure out if he or she is unhappy about my presence. If I think he or she does not want me around I will stop my observations and let you know. Then you and your child can decide together whether you both would like the study to continue.
Participation in the study may not be of direct benefit to your child or yourself. However, your child's participation may help others like him or her because learning about his or her experience will help health professionals give better care.

If you have any further questions or concerns, I will be pleased to answer them. You can reach me at home at 425-7854, or at my office at 978-2134. If you and your child wish to participate in the study, I will ask you to sign a consent form. I will also explain verbally and in writing what I am doing to your child and ask him or her, if possible, to sign an agreement form.

Thank you for your interest and time.

Esther Ignagni, B.A.Sc.
Consent Form for Parent(s) or Guardian(s)

Title of Research: Ethnography of the daily lives of children fed by gastrostomy tube.

Investigator: Esther Ignagni, B.A.Sc.
Phone: (416) 978-2134

Supervisor: Dr. Heather Maclean
Department of Nutritional Sciences, Faculty of Medicine, University of Toronto.
Director, Centre for Research in Women’s Health

I have been asked to give consent for my child to participate in a study exploring the experience of daily life for children who have a gastrostomy tube. It has been explained to me that participation in the study involves the following:

Esther Ignagni will accompany my child through his or her daily activities on three separate days at our convenience. This means she will meet my child at home in the morning, and proceed with him or her to school or daycare and return home at the end of the day. If my child lives in a long term care setting, Esther will meet him or her in the morning, participating in all his or her daily activities until the evening.

During the time of the observation, either myself or my child can ask to not be observed either temporarily or permanently, or withdraw from the study at any time.

I understand that other people Esther Ignagni meets with in the course of my child’s day will be told briefly that she is a graduate student conducting field research on the daily lives of children with neurodevelopmental impairments who have gastrostomy tubes.

Any decision regarding my child’s participation in the study will in no way affect the services my child is currently receiving through the Bloorview-MacMillan Centre.

Everything Esther Ignagni observes or is told will be kept confidential, except when otherwise required by the law, such as in suspected child abuse. At no time will any names or identifying information of my child or anyone else my child is in contact with be used in any reports that may be written about this study.
I understand that there is a risk that my child may feel uncomfortable or distressed about being observed. Esther Ignagni will be informed how to assess this with my child and will discontinue observation if this occurs.

I understand that my child may not directly benefit from the study. However, the information may be useful in helping other children and families in similar circumstances.

The days and times that Esther Ignagni will be observing my child will be as follows:
(To be determined with the parent)

She will call me two days in advance of each observation day to confirm. I can change these arrangements at any time.

I am signing two copies of this consent form. One will be kept by myself and the other which will be kept by Esther Ignagni in a secure location.

I hereby consent to having my child participate in the study described above.

Signature ____________________________

Date ________________________________
Assent Form for Participants

I agree to participate in a study about the mealtimes of children have a gastrostomy tube. This means that Esther Ignagni will have be accompany and observe me through a meal on up to three different days.

I understand that anything I say and do is confidential and my name will not be used in any of the reports that are written about this study.

I understand that my participation in the study is voluntary. I can ask Esther Ignagni to leave me at any time and I can stop being in the study if I do not want to be in it anymore.

I understand that other people Esther Ignagni meets while she is with me will need to know what she is doing. She will tell them that she is a student doing a project on the daily lives of children with neurodevelopmental impairments who have a gastrostomy tube.

I understand that I will not have any direct benefit or good things happen from being in the study. I may feel awkward or uncomfortable about having someone be with me for a day.

I understand that this study might help other children like me because health care professionals will learn things that will help them care for these children better.

I am signing two copies of this form. I will keep one and the other one will be kept by Esther Ignagni.

Participant's Signature:

Date:

I consent to having my child ________________ participate in the study described above.

Parent or Guardian's Signature:

Date:
Information Sheet for Potential Observational Settings

My name is Esther Ignagni and I am a graduate student in the Nutritional Sciences department at the University of Toronto. I am conducting a study under the supervision of Dr. Heather Maclean. The purpose of this study is to explore the mealtimes of children who are fed by a gastrostomy tube.

This study involves my accompanying several children throughout their mealtimes in order to observe their usual activities and interactions. Through this I hope to gain an understanding of the potential role and meaning of feeding and mealtimes for these children. ______________________ is one of the participants in this study. This means I will be observing ______ while (he or she) is at _____________________. (name of institution)

While I am with (name of participant) at your organization, I will take part in all the activities he or she normally does. I will not provide any direct care for (name of participant) while I am with him or her, but will leave that to people who are normally his or her caregivers. Because I am interested in how other people interact with this child, I will be recording the interactions your staff have with (him or her); specifically those which concern eating or gastrostomy maintenance. Therefore, I will explain who I am and what I am doing to your staff. Everything I see and hear while at (name of organization) will be kept confidential. The name of your organization and the names of staff members will not appear in any report of this study. When the study has been completed, all identifying information will be destroyed, however my field notes and computer disks will be kept for six years.

(A paragraph specifying the times that I will accompany the participant will be included).

If you have any further questions, I will be pleased to answer them. You can reach me at my office at 978-2134.

Thank you for your time.

Esther Ignagni