

A PILOT STUDY
OF THE IMPLEMENTATION OF A COORDINATED
MULTIDISCIPLINARY PROGRAM
TO GUIDE CASE FINDING AND INTERVENTION
WITH CHILDREN WHO FAIL TO THRIVE

by

ELIZABETH HELEN THOMLINSON

A thesis
presented to The University of Manitoba
in partial fulfilment of the requirements
for the degree of
Masters of Nursing

Winnipeg, Manitoba

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Once a child is born, it is no longer
in our power not to love it nor care about it.
Epictetus, 117 AD

ABSTRACT

Although failure to thrive (FTT) constitutes 1-5% of admissions to paediatric hospitals and 10-20% of ambulatory care cases in industrialized countries, there has been a paucity of research on intervention strategies with the children and their parents. The syndrome does not present as a dramatic, immediately life threatening illness, but rather as a slow stunting of a child's growth and developmental potential. Causes of FTT in children may be organic, non-organic (environmental), or a combination of both. Previous research, particularly in the United States and Australia, has focused on the characteristics of the children and of the mothers, with less emphasis on the family and parent/child interactions in the context of the syndrome.

In this pilot study the researcher served as coordinator in a multidisciplinary approach to intervention with five of 54 children admitted with FTT in one seven month period to Children's Hospital. The children and their families were followed for 6 to 10 months following diagnosis of FTT. The objective of the study was to determine the strengths and weaknesses of a proposed intervention program.

Based on observations and interviews with parents and professionals involved in the study, the most prevalent finding was substantiation of the need for in-depth assessment prior to planning crisis care and designing long-term follow up. A core case management team, to which other professionals could be added based on identified needs, should be comprised of a nurse coordinator, a consulting physician, a social worker and a dietitian. Continuity of care, the prevention of gaps and/or duplication in service delivery, and long term case management would result from the coordinated interdisciplinary strategy. One contact person for families and professionals would facilitate communication, resource access, and service implementation. The benefits of the program and the constraints experienced during the process of development and implementation of the program are examined. The necessity to interrupt the cycle of FTT with its negative sequelae for the affected children, and the implications for nursing practice and for future research are discussed.

ACKNOWLEDGEMENTS

This study was based on the desire to seek successful intervention strategies for children who are not growing and thriving as they could. Throughout my efforts I have been fortunate to be supported by many individuals who recognized the very real need to help these children and their families. I wish to thank the Manitoba Health Research Council and the Health Sciences Centre Research Foundation for their support in funding the research.

My thesis committee collectively provided research expertise and guidance throughout the process. Dr. Erna Schilder, chair of the committee, questioned, encouraged, and forced me to broaden my approach to clinical problems. As always, Dr. Schilder's compassion for patients and her belief in the need for clinical research to improve patient care came to the fore in our discussions.

Dr. Ken McRae taught me that it is possible to never lose one's joy in the development of children. His clinical expertise and teaching skills were evident during the many sessions I attended at the Child Development Clinic. I want to thank Dr. Ina Bramadat for her assistance by forcing me to clarify those sections that to me seemed patently clear but on second reading required definition.

There were many others who listened to the development of the program proposal. Betty Currie served as facilitator, encourager, program analyzer, and friend throughout the process. I value Margo Buck's abilities and teaching skills in working with families stressed by many problems. A special thank you to Brenda, Debbie, Enid, Kathleen, Lesley, Leslie, and Roma at the Child Protection Centre and to the nurses at Children's Hospital for help, over what seemed to be many years. To my fellow graduate students, Wanda, Marie, Sue, Kathy, and Sharon, thank you. Thanks to Betty Currie and John Fox for proof reading endless pages.

Most of all, I would like to thank the children and their families who participated with the hope of developing a program that would benefit future children who are failing to thrive. Without them the research would not have been possible.

DEDICATION

To my husband, Jim, who was a constant support,
and to my sons David, Michael, Mark, and Eugene
who allowed their student mother to live with them.

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PART I

INTRODUCTION AND APPROACH

CHAPTER I

STATEMENT OF THE PROBLEM

Tot 'Starved to Death' Inquest told
Neglect cited in Tot's Death

These headlines of the Winnipeg Free Press in August, 1989 caught my attention. The pilot study into children who fail to thrive for reasons other than major medical disease insults was already in progress. More than two years previously, an 18 1/2 month old child had "literally starved to death" although she had been seen by health care professionals 21 times in her brief life. "While the baby was dying, no one - not numerous nurses, parents, grandparents, social workers, a paediatrician or an entire community - brought together the necessary information that would have revealed the baby's problem " reads a quote from a medical officer. During the inquest the recommendations included: a) improving education in acceptable standards for the health care of children; and b) ensuring support programs in parenting skills, and normal growth and development be taught through community funded agencies.

No one person was able to pull together the segments of information that various persons had about the child's physical condition and the environment in which the child and her caretakers lived. It was decided that the child's weight loss had occurred over a period of six months. Nothing dramatic or immediately life threatening prompted emergency services; just a slow steady decline with no one really noticing. This, unfortunately, is the picture that a child who is failing to thrive presents, and because no one was able to conceptualize the total picture of that little girl's life, parents, professionals, and community were forced to accept responsibility conjointly for the death of that child.

Failure to thrive (FTT) syndrome was originally described in the early 1900s, however, the full extent of its impact on the children concerned is only now being realized. The negative effects on children of institutionalization have been known since early in the century, but the recognition that children in families could be similarly deprived is a more recent phenomenon (Durand, 1975). The condition of failing to thrive, characterized by lack of physical growth and delayed psychosocial maturation, affects children at a critical stage in their development, often remaining invisible for a period of time. Medical assistance may only be sought when a child's physical condition deteriorates to the point that weight loss becomes readily discernible to persons outside the family.

Failure to thrive has been classified according to the perceived etiology as:

- 1) organic, - physical insult is basis for the problem, and
- 2) nonorganic, - whereby psychosocial factors are the cause of the syndrome.

The separation into disparate etiologies is slowly losing favour among health care professionals. Peterson, Washington, and Rathbun (1984) are among the growing numbers of professionals who stress that there are emotional risks associated with organically based problems. In turn, malnutrition is the physical cause of the growth failure that occurs as a result of psychosocial problems. This amalgamates both etiologies and presents a more comprehensive view of this complex syndrome.

The researcher's interest in FTT originated from 16 years as a head nurse on a paediatric unit of a rural hospital. During that period there were a number of children admitted to the hospital who were not "growing as they should". Each child underwent a series of tests, all with normal results. The home lives of these infants and children were chaotic and, on occasion, abusive. There were well intentioned but scattered efforts at treating the problem, with little or no attempt to assess or intervene in the homes. Of those FTT children four are particularly unforgettable. Two of the children were, within three to

four years of diagnosis and following multiple admissions to hospital, severely physically abused; one suffered permanent brain damage. Both of these children were apprehended by child welfare agencies and permanently placed in adopting homes. Another child was relinquished in a voluntary placement while the last child remained a slow grower in her own home. The frustration experienced by all the professionals, in their attempt to interrupt the cycle of FTT, prompted the researcher to explore whether effective treatment strategies were utilized in other parts of Canada and the United States. The experiences of ineffectively managing the interventions with these children and their families provided the incentive for this research project.

The relationship between a child and his/her primary caretaker, usually the biologic mother, is a learned one. The quality of care provided the child transmits a sense of trust, meaning and satisfaction; a satisfaction that is mutual between the mother and the child (Bowlby, 1969). Erickson (1950) early suggested that the first demonstration of trust in a baby is the ease of feeding, the depth of sleep, and relaxation of the bowels of the baby. As well as the contact comfort and clinging, considered essential to a child's development (Bowlby, 1969), sensory stimulation in the environment is necessary for the child to develop an ability to relate to others (Yarrow, 1968). The lack of a nurturing relationship, with or without sensory deprivation, may manifest in a multitude of ways:

apathy, social unresponsiveness, lethargy, decreased mobility, sad and apprehensive facial expression, irritability, poor sleep, pallor, poor appetite, failure to gain weight, poor muscle tone, reluctance to touch objects, frequent autoerotic activity, decline in developmental quotient, reduced ability to discriminate, and lessened interest in exploratory behaviour... (Durand, 1975, p.273).

The physical manifestation of growth failure may be a result of, and exacerbated by, this lack of nurture and sensory stimulation.

In the United States it has been suggested that children who fail to thrive comprise 10-20% of rural and urban ambulatory care patients and 1-5% of admissions to paediatric

referral hospitals (Drotar, 1988). In 1983, the Massachusetts Department of Public Health reported that 159 of 413 of children seen in the Boston City Hospital demonstrated severe deficits in their weight for height (Drotar, 1988). The prevalence of the syndrome in Canada has not been documented but there is little reason to suspect that the incidence of failure to thrive in Canadian children is any less than for American children.

Increased antisocial behaviour, growth deprivation, and decreased language and verbal skills affecting educational opportunities are long-term negative sequelae which result when effective intervention is not instituted (Elmer, Gregg, & Ellison, 1969; Oates, 1986; Oates, Peacock, & Forrest, 1984, 1985). Sherrod, O'Connor, Vietze, and Altemeier (1984) found a positive correlation between the factors contributing to the development of FTT and the factors contributing to child abuse, indicating that FTT may be a precursor to abuse. The earlier an established problem is recognized and effective management initiated the greater the potential to prevent or reverse severe and/or intractable disorders (Drotar, 1985; Steele, 1986).

The costs of hospitalization, foster care, mental health treatment and lost educational potential are extensive for the child, the family, and ultimately, for society. Early recognition of the problem and intervention may lessen the long-term psychosocial consequences. Because few treatment programs exist there have been no long-term studies to determine the effects of intervention.

In current literature the problem of FTT is defined and the physical and psychosocial signs and symptoms of the syndrome are described. Actual care of children with FTT has centred on the search for the physical causes of the child's condition (Drotar, 1985). Frank (1985) stated that FTT reflects an extremely complex etiology that requires a coordinated effort to provide medical, nutritional, developmental, and psychosocial assessment and intervention for the child and the family. Failure to thrive has become an

all encompassing term to describe children who are not growing as might be expected. Currently failure to thrive is being redefined as a category of symptoms rather than a specific illness (Durand, 1975). Because of the nature of the syndrome, intervention must reach beyond the hospital or ambulatory care setting to the community.

Nurses, both in the community and in hospitals, work with children at risk for FTT and with their families, as well as with those who are affected by the syndrome. Knowledge of the complex nature of the condition and of the multidisciplinary intervention required should assist nurses in seeking out and intervening with FTT children. Because FTT is a complex syndrome, the public health nurse, assessing a small-for-age child in the home, must be cognizant of the criteria and methods used to evaluate the syndrome (Bray, Brosnan, & Erkel, 1989). Reliance on any one set of variables may result in an incomplete assessment of the child's condition; physical, nutritional, developmental, social and environmental variables must be considered.

Many disciplines work within tertiary care centres where FTT children are admitted, but few programs exist that provide an integrated approach to intervention (Dennis Drotar, personal communication, Cleveland, Ohio June 13, 1988). Professionals who work with FTT clients must be aware of the need to develop long-term interventions for these children and their families. In the experience of the investigator, children who are failing to thrive have presented such a challenging and difficult problem that many professionals have shied away from establishing long-term treatment. These children have been ill served by a system in which they are admitted to hospital, administered multiple tests to rule out organic disease, and then discharged home with a statement that this problem is a "social problem". These children have not presented as startling or as dramatic problems as those who are critically ill or abused and have therefore, taken lesser priority than children with visible organic problems.

The investigator conducted a study reviewing the charts of children whose diagnosis contained the Diagnostic Services Manual (DSM) III listing of failure to thrive. The study results showed that there was no consistent pattern of follow-up upon discharge from hospital for these children. Psychosocial assessment of family functioning and home environment was not instituted. Multiple medical investigations were conducted to determine whether a physical cause could be found for the growth failure. Health care and child welfare professionals in the community were consulted in 10 of 59 cases. This lack of in-depth assessment, of multiple investigation, and uncoordinated or absent long term intervention was consistent with the findings in a study by Drotar, Malone, Negray and Dennstadt (1981). These findings served as an impetus to conduct further studies into the method of investigation, treatment, and follow-up for children who are failing to thrive.

Research Questions

Coordinated multidisciplinary teams actively engage in intervention programs for children who have chronic illnesses and develop failure to thrive secondary to these illnesses. The lack of coordinated programs to provide intervention for children who are failing to thrive based on environmental causes, and for their families, prompted this investigator to consider the following questions:

1. What are the interventions needed for children who are failing to thrive?
2. What are the benefits of instituting a nurse coordinated program for children with failure to thrive based on environmental reasons?
3. What are the constraints involved in developing such a program?
4. Would it be possible to measure benefits to the child who is failing to thrive and/or to the family over a limited period of time?
5. Would it be possible to determine what interventions initiated as part of a pilot study were effective and which were not?
6. What type of program should be developed that would benefit these children and their families, including the various disciplines that may be necessary to promote family functioning?

Because there are few established programs on which to base the development of an intervention strategy, there was an identified need to conduct a pilot study to seek initial answers to these questions. Although knowledge of a general nature is gained from the

literature, knowledge of the particular must come from the "researcher's involvement in the setting with the subjects, operations and measures" (Prescott & Soeken, 1989, p.60). It is important, prior to full-scale implementation, to ascertain whether the treatment, as is currently practised, contains all the elements it theoretically should contain. A trial of the intervention strategy should identify any likelihood of threats to the intervention. Nurses, with their backgrounds in medical and social sciences, are suitable candidates to coordinate the activities of team members as they analyze and plan the needed treatment steps.

Objective of the Study

In this pilot study the investigator tested a nurse coordinated multidisciplinary intervention for children who are failing to thrive. The researcher developed the program in conjunction with the health care professionals who are involved in the care of FTT children at a tertiary care facility in a mid western Canadian city. It was expected the following benefits would be demonstrated from the program:

- a) enhanced growth and physical and psychosocial development of FTT children,
- b) additional supports to aide family functioning,
- c) improved health and psychological functioning of the child and the family, and
- d) the reduction of long term health care costs.

It was expected that the program would therefore benefit FTT children, their families, and the community. Health care professionals would acquire added knowledge of the syndrome, its causes and effects, and the use of multidimensional interventions. Positive results would serve to empower those involved in the effort to include multidisciplinary efforts in other areas of practice.

CHAPTER II

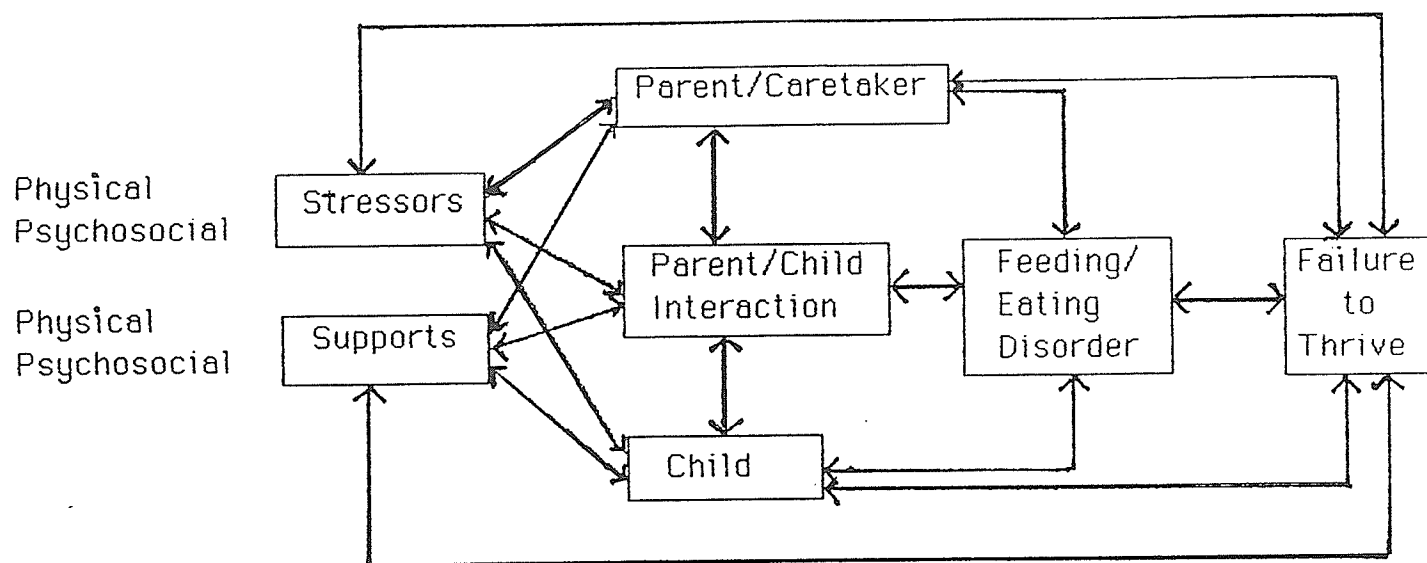
CONCEPTUAL FRAMEWORK

In the study the researcher incorporated the conceptualization of the problem within three theoretical frameworks that included the development of the syndrome, the maintenance of the symptoms and the conduct of the pilot study. These included an etiological model of growth deficiency, systems theory and action research. The study, however, did not test theory but was theory generating. As such, it did not derive from a theory, but rather from the described and reported experience of professionals, the experience and observations of the investigator, and of others, involved in health care delivery to this clientele.

Biopsychosocial Model

FTT in children has been viewed on a linear continuum with biomedical and psychosocial etiologies on opposing ends of the continuum (Bithoney & Dubowitz, 1985; Roberts & Maddux, 1982). This conceptualization of the etiology of the problem is not adequate as there is often a mixing and overlapping of the variables involved. To enhance understanding and clinical management of FTT, Bithoney and Dubowitz (1985) introduced a biopsychosocial conceptual framework involving an interplay of organic and psychosocial factors.

FIGURE 1 - Biopsychosocial Framework



Adapted from Bithoney and Dubowitz (1985).

Basic to this model is the premise that no variable exists in isolation but that each is in constant interaction with the other variables. Included in the model is the transactional nature of the child/caretaker interaction which is a dynamic ongoing process. The physical and psychosocial stressors and supports have an impact on the parent/caretaker, the child, and their interaction. Negative results may present as a feeding/eating disorder which may evidence as failure to thrive. A child who is failing to thrive will in turn affect all of the variables involved, exacerbating an already difficult problem. This framework of the child and his/her family is a part of the larger conceptual model of family systems theory.

Systems Theory

Family systems theory, which includes the larger community system, serves as the all inclusive framework within which the child, the family, and the environmental supports and stressors act and react (Braden & Herban, 1976; Fawcett, 1985; Minuchin, 1985). A child/mother/family unit forms when a child is born. In a systems framework, abusive and neglectful actions of one member are not seen as the expression of the individual pathology of the family member, but are viewed as part of the overall functioning of the family (Asen, George, Piper, & Stevens, 1989; Withrow & Fleming, 1983). External forces from the environment both affect and are affected by this unit during its growth and development.

These external forces may involve family and friends, the neighbourhood, and the social, cultural, and political setting in which the family lives and operates. At any stage in the evolution of this family system, stresses and deviations may lead to maladaptive functioning. Families must be studied over time to avoid misconstruing adaptation to external stressors, such as extreme poverty, as family psychopathology. Careful analysis of the interactions within the family system and in the larger environment is necessary before any decisions are to be made. For units where dysfunctional interactions have created problems, and are maintaining them, observable changes in the family system and in the described patterns of behaviour are necessary to ensure that effective intervention has been instituted.

FTT only occurs within a context that allows the syndrome to develop and be maintained, as in an isolated family that has no supportive interaction with extended family or friends (Gagan, Cupoli, & Watkins, 1984). If there is one caretaker within that family system who can provide consistent loving care to the child, FTT may be prevented or ameliorated. A child who is failing to thrive, because of nonorganic or environmentally based reasons, may be interpreted as symptomatic of a family in distress (Stephenson, 1980).

The community at large is affected by the long-term negative sequelae that occur as a result of not adequately intervening with children with environmentally based FTT.

Action Research

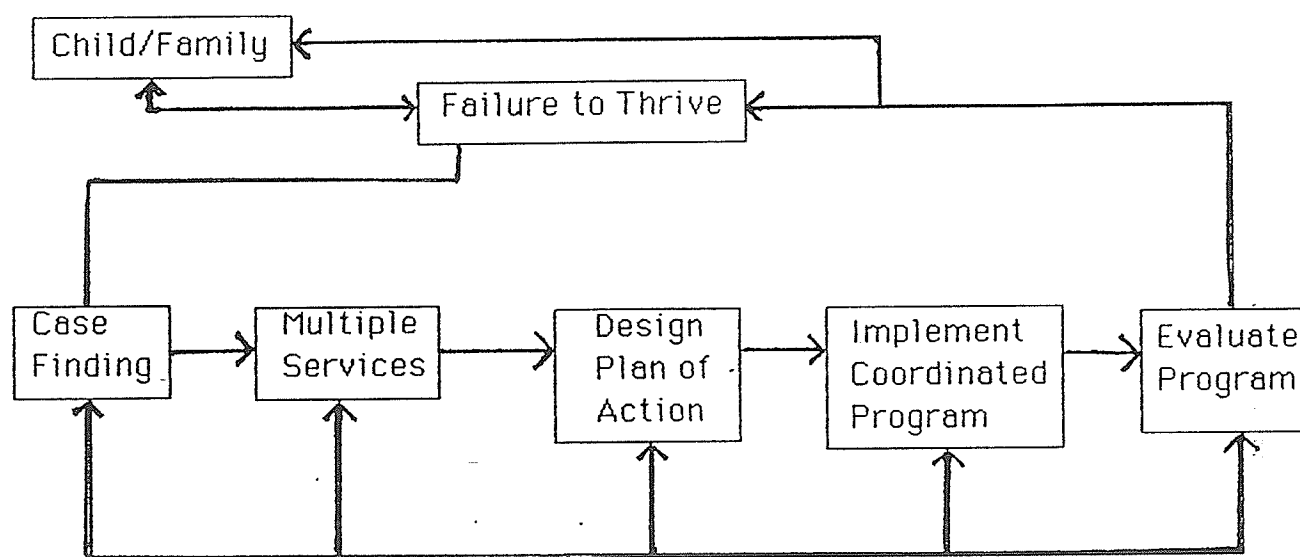
The development of FTT, and the interventions required for treating the syndrome, present a very real problem for the children involved, their families and the health care professionals attempting to care for them. The complete conceptualization of the child's world, as it is and as it could be, and the potential for changing that reality, provides the theoretical background for practitioners. Because action research is concerned with the parameters of a particular problem, and with introducing change while exploring that problem, it provides a framework to guide treatment modalities for the complex problem of FTT (Foster, 1972). In the arena of social change "research that produces nothing but books will not suffice" (Lewin, 1946).

To deal with this critical social and medical problem, researchers, practitioners, and the child/mother unit must collaborate to initiate change (Susman & Evered, 1978). By acting on, or in, the social system the researcher may both change the system and, generate critical knowledge about it. The ultimate purpose of this action research is to produce valid generalizations about how the FTT children and members of their social systems design their daily lives. In turn, this knowledge would provide a basis for practitioners to use in the development of solutions to these complex problems (Argyris, 1982).

The actions of investigating the parameters of a problem, intervening to produce change, and generating theory about the background and the intervention occur simultaneously and not independently of one another (S. Kappeli, personal communication, October, 1989). Kappeli noted that the researcher must be competent in the field he/she desires to change. The researcher does not need to know all the answers but must be

available to work with those in the field from whom the initiative for change must come (Kappeli, 1988). The researcher cannot afford to be strictly theoretical but must have practical knowledge of the problem and potential intervention strategies.

FIGURE 2 - Action Research



Rapoport (1970) maintained that the researcher would, in collaborating with the client system, sacrifice detachment and independence in order to produce valid, useable information. This knowledge, generated in the context of social interaction, would then be suited to the cognitive limits of human beings acting in real situations (Argyris, Putnam, & Smith, 1985). Argyris (1982) contended that, to be directly usable by concerned individuals and organizations, theories should be the same as those in use everyday by the persons involved in the specific situations.

Action research generates theory to serve as a guide in the diagnosis of problems and in the production of possible courses of future action (Susman & Evered, 1978). This theory should identify patterns that, suitably combined, would be useful in many situations (Argyris, Putnam, & Smith, 1985). Thus, action research is able to contribute to knowledge in social science as well as to knowledge in everyday life. Although the scientist is part of the experimental treatment, the actions of the interventionist, and the theory-in-use behind these actions must remain clear, explicit, always observable, and subject to empirical testing to maintain the scientific rigor of the research (Argyris, 1982).

CHAPTER III

LITERATURE REVIEW

The reporting of research on FTT has concentrated on the diagnosis of the problem, the characteristics of the child and the primary caretaker, mainly the mother, and the description of the family. Failure to thrive is operationally defined according to physical growth parameters of the child. Frank and Zeisel (1988) emphasize that the diagnosis of FTT should be based on anthropometric criteria alone and should not include, as has been by some authors, disordered behaviour and development.

Definition

FTT is operationally defined by the use of the National Center for Health Statistics percentile charts (Hamill, Drizd, Johnson, Reed, Roche, & Moore, 1979). These charts are age and sex appropriate for North American children. The anthropometric parameters used are weight, height, and head circumference. The percentile lines on the charts represent the percentage of the population of children who fall below the lines on average.

FTT has been defined as: (a) weight consistently below the 3rd percentile for age (Berwick, Levy, & Kleinerman, 1982); (b) weight for height below the 50th percentile curve (Berkowitz & Sklaren, 1984); and/or (c) the failure to maintain a previously established pattern of growth (Cupoli, Hallock, & Barness, 1980). A drop of two percentile lines on the chart is an indication of serious growth deficits and of the need for concerted efforts at assessment and intervention.

The etiology of growth failure is inadequate caloric intake or usage by the child

because of physical or environmental reasons (Field, 1984; Goldstein & Field, 1985). It is now realized that in all cases of nonorganic FTT, and in most cases of organic FTT, the primary biologic insult is malnutrition. Thus, all children with nonorganic FTT are suffering from a serious organic problem: primary malnutrition (Frank & Zeisel, 1988). Low dietary intake, whatever the cause, results in decreased nutrient availability at the cellular level giving rise to growth retardation, and indicating poor child health (Martorell, 1989). At severe levels of nutrient deficiency linear growth ceases and it becomes necessary for the body to use tissue reserves as an energy and nutrient source to maintain vital functions. At less severe stages it may be possible to cope by slowing down growth and by decreasing physical activity.

Seckler (1980) hypothesized that people who are short in stature because of mild to moderate malnutrition in childhood are nonetheless healthy and well-adapted. He argued that, in childhood, the body adapts to low nutrient intake by reducing its rate of growth, thus maintaining equilibrium in physiological functioning. The resultant lowered growth rate and short stature leads to no other "impairment" (Seckler, 1980, p.224). According to Seckler, malnutrition is evidenced by physical debilities other than short stature.

This hypothesis has been criticized by Scrimshaw and Young (1989) in their analysis of the consequences of low dietary protein and amino acid intake, and of the physiological and social limits to restricted energy intake. One result of low protein intake may be a diminished integrity of the immune system and more serious consequences of severe infection (Pelto & Pelto, 1989). While clinically overt deficiencies are dramatic, it is strongly suggested that mild to moderate malnutrition reduces cell mediated immunity in children decreasing disease resistance (McMurray, Loomis, Casazza, Rey, & Miranda, 1981). Decreased energy intake results in weight loss as first fat and then lean body mass is depleted (Scrimshaw & Young, 1985).

Most studies on mild to moderate malnutrition have been conducted in developing nations, but the findings are as applicable to those suffering from the effects of inadequate intake in an industrialized country. There have been suggestions that, if no physical basis for slow growth are found, then this is the child's normal growth pattern. Without thorough study of all aspects of the child's life, this is an inadequate explanation that may have dire consequences for the child.

Inadequate intake first results in decreased weight, an indicator of acute or recent malnutrition, with length drop off only occurring after continued diminished dietary intake, indicating chronic malnutrition (Frank & Zeisel, 1988). Prolonged shortfall in intake will produce a reduction in head circumference; an indication of the extreme severity of the problem. Caloric intake required to maintain body weight varies according to age: a) from birth to five months babies require 20-30 grams per day, b) from five to twelve months they need 13 grams per day, and c) after one year infants use seven grams per day. To overcome deficits and to catch up weight loss intake must be greater than those cited for each age.

Etiology of Failure to Thrive

Organic Causes

Organic failure to thrive is due to a diagnosable physical disorder that is judged to be the sole basis for the syndrome (Berkowitz & Sklaren, 1984; Casey, Wortham, & Nelson, 1984). These organic causes may include but are not exclusive to: central nervous system disease, such as cerebral palsy or congenital neurologic anomalies; idiopathic hypercalcemia, chronic respiratory, cardiac or kidney disease; gastrointestinal tract anomalies or malabsorption syndromes; endocrinopathies; and mechanical feeding difficulties such as reflux. Several studies have been conducted into the impact that serum zinc and copper have

on growth status of children (Laitinen, Vuori, Dahlstrom, & Akerblom, 1989; Walravens, Hambridge, & Koepfer, 1989). Findings of these studies have been inconclusive.

Nonorganic Causes

Early 1960's literature focused on "maternal deprivation" as one of the major reasons that children failed to grow and thrive (Elmer, Gregg, & Ellison, 1969). Other researchers noted that this term was a vague, all encompassing term designating a lack of mother, of food, of physical, social and emotional stimulation (Ephross, 1982; Oates, 1984; Roberts & Maddux, 1982). It is accepted that FTT may be the result of a disturbed interaction between the primary caretaker (usually the biologic mother), the child, and the environment. As a result of maladaptive interaction between these systems, dietary intake is insufficient to promote weight gain and growth (Bithoney & Newberger, 1987; Goldbloom, 1982; Stern & Casey, 1984). Stresses in the environment affect this interaction negatively while supports positively influence this interaction.

From this interactive viewpoint, the child's failure to grow is a response to early disturbed mother-infant relationships (Altemeier, O'Connor, Sherrod, & Vietze, 1985; Bradley, Casey & Wortham, 1984; Haynes, Cutler, Gray, O'Keffe & Kempe, 1983). Infant temperament, poor health of the infant, current family stresses, and maternal difficulties in nurturing are suggested as factors having a potential impact on the reciprocal interactions between the mother and infant (Kotelchuk & Newberger, 1983; Pollitt & Eichler, 1976). Nonorganic failure to thrive has been conceptualized as a breakdown in the reciprocal attachment process which develops in early infancy between the infant and the caretaker/mother and which underpins the emotional, physical, and cognitive development of the child (Fraiberg, 1980; Singer, 1987).

In families with an overly intense parent/child interaction the child, although deeply

attached to his/her parents, may use food refusal as a means of attaining autonomy (Hathaway, 1989; Woolston, 1983). These families may actually be functioning well, with a child who exhibits appropriate or precocious development. Because there is no opportunity for the child to become independent, to gain control of the situation he/she refuses to eat.

Combination of Causes

More recently researchers have suggested that a combination of organic and nonorganic factors contribute to a child's growth failure (Berwick, 1980; Bithoney & Dubowitz, 1985; Casey, Wortham & Nelson, 1984). The separation of etiologies into two distinct camps promoted the notion that physical and emotional factors were mutually exclusive. Children who have a physical basis for their FTT may experience interactive difficulties with their caretakers, while malnutrition has effects on the emotional state and behaviour of infants, children, and adults (Homer & Ludwig, 1981; Kempe & Goldbloom, 1987). Whereas the etiology of growth failure remains complex, multifactorial, and unclear, the outcome is that the child is not given, refuses, or is not able to absorb calories in sufficient quantities to grow (Bell & Woolston, 1985; Ramsey & Zelazo, 1988).

Characteristics of Failure to Thrive

The Child

On physical examination the child may appear emaciated, pale, weak, with little subcutaneous fat and with decreased muscle mass (Kempe, Cutler, & Dean, 1980). Wasting of the gluteal muscles reveals loose folds of skin at the buttocks (Oates, 1984). These physical signs are accompanied by various behavioral indicators.

Several researchers noted that it is difficult to ascertain whether the physical manifestations noted of FTT children are a cause or a result of the growth failure. Funke-

Furber and Roemer (1978) suggested that a child who has impaired "...reflexive behaviours (sucking, crying, clinging, eye-following, smiling) or who is difficult to cuddle or console..." (p.31) can adversely affect the mother's view of her parenting abilities. If an infant's feeding behaviour from birth includes "refusing the nipple, falling asleep or crying during feeding, having a poor appetite, positing and vomiting frequently and fighting the person who feeds him" (Oates, 1984, p.97) it is quite possible the child will fail to thrive.

Rosenn, Loeb, and Jura (1980) found many FTT infants showed such interest in inanimate objects that they shut out social encounters. FTT infants would push away when being held, arching their backs to further distance them from the holder (Moore, 1982; Powell & Low, 1983). Behaviours these researchers noted that coincide with those found in other studies were: listlessness, with decreased body activity; excessive crying and irritability; flexed hips and knees; expressionless face; infantile posturing in which the arms were held out, flexed at the elbow with the hands up; and rumination (voluntary vomiting regurgitation or vomiting of ingested food back into the mouth) (Powell, Low & Speers, 1987; Singer, 1987).

Feeding disturbances included poor appetite, poor suck, crying during feedings, vomiting after each feeding and refusal to switch from liquids to solid food (Magreb, 1978; Pollitt & Eichler, 1976). These children often presented as hypervigilant, with a wide-eyed searching appearance; a "radar-like" gaze (Glaser, Heagarty, Bullard, & Pivchik, 1968; Goldbloom, 1982; 1987). To describe this wide gazing expressionless appearance the term 'silent watcher' was coined. In a study of postnatal conditions of FTT children Altemeier, O'Connor, Sherrod and Vietze (1985) noted the pregnancies were of slightly shorter gestations of 38-39 weeks, the babies were shorter in length than the average, and mothers had more difficulty feeding the babies. More of the babies also had unresolved postnatal health problems, such as the need for bilirubin retesting, on discharge from hospital.

Sherrod, O'Connor, Altemeier, and Vietze (1985) noted a positive correlation existed between the number of illness episodes during a child's first year and the likelihood of FTT. Otitis media was one of the more frequently noted illnesses from which the children suffered. Frank (1985) reported that Bithoney found significantly higher blood lead levels in FTT children. High blood lead levels are associated with anorexia, abdominal pain, and vomiting and may be a cause, or a result, of the FTT. Anaemia resulting in lethargy, decreased appetite, delayed development, and perceptual abnormalities is another condition that has an undetermined cause and effect relationship in FTT (Bithoney & Dubowitz, 1985).

When the infant's condition deteriorates, with weight loss and wasting of muscle tissue, and as the excessive pallor becomes more pronounced the already damaged mother/child interaction may be aggravated (Kempe, Cutler, & Dean, 1980; Moore, 1982). The mother who is usually the primary, and often only, caretaker may perceive the child's condition as a critical comment on her skills.

The Mother

Newberger, Hampton, Marx and White (1986) found that the majority of mothers in their study shared the common thread of a neutral assessment of their own childhood. An underlying theme was the inability of the mother/caretaker to remember anything pleasant about her own childhood (Altemeier, O'Connor, Sherrod, & Vietze, 1985; Haynes, Cutler, Gray, & Kempe, 1984). The mother often had a history of profound emotional and physical deprivation in her childhood and these "ghosts" in her past interfered with her ability to parent (Fraiberg, Adelson, & Shapiro, 1980). Roberts and Maddux (1982) noted that many of these "FTT mothers" (p.218) had low self-esteem, were passive, lonely, isolated, helpless, desperate, angry, and anxious.

Roberts and Maddux (1982) also noted that the mothers in their study often were young and had not developed the maturity or sense of responsibility necessary to undertake child care. They found that some of these mothers were overwhelmed by the children they considered a 'final straw' in an accumulation of problems. The mothers who lacked positive feelings toward the child rarely held, cuddled, or talked to her/him (Casey, Bradley & Wortham, 1984; English, 1979; Yoos, 1984). Some mothers appeared listless, detached, and apathetic, thus creating even more difficulty in attaching to a child that may be irritable and difficult to calm (Chatoor, Schaefer, Dickson, & Egan, 1984; Chatoor, Schaefer, Dickson, Egan, Connors, & Leong, 1984).

One other distinct group of mothers of FTT babies was identified in a study by Kotelchuk and Newberger (1983). These were the mothers who were young and immature and who lacked knowledge of growth, development, and adequate nutritional requirements of their infants. These mothers did not know what to expect in raising their children nor how to respond to them. This group of mothers reacted positively to assistance and education with the result that their children grew and developed psychosocially.

Many mothers had suffered a series of losses throughout their lifetime. They had experienced the deaths of those to whom they felt close. For persons who lack a strong support system, the loss of even one friend is devastating, but for those who lack this system, the loss is disproportionately high (Altemeier, O'Connor, Sherrod, & Vietze, 1985).

The Father

Little research has centred on the fathers of FTT children (Drotar, 1988; Elmer, 1960). Iwaniec, Herbert, and McNeish (1985A; 1985B) noted that these fathers were absent from the relationships, emotionally if not physically. The effect that paternal functioning has on maternal competence and on the development of FTT children has yet to be fully

documented (Drotar, 1988).

The Family

Despite the fact that clinicians have observed the association of "severe family dysfunction with FTT for a number of years..." the family context of FTT is the least well understood feature of this condition (Drotar, 1985, p.32). Oates (1984) reported that the mother frequently was in a seriously disturbed marital union or one in which the partner was absent. This lack of intrafamilial support for the mother/primary caretaker may result in an overload situation wherein the mother's personal resources are depleted by claims for care and by family tension (Drotar, 1988; Drotar et al, 1985). These dysfunctional families had difficulty establishing firm boundaries between the spousal system and the children. Parental conflict then spilled over into areas that were not appropriate.

Problems of poverty, unemployment, inadequate housing, and lack of transportation may serve to isolate the families (Moore, 1982). In contrast to other studies, Glaser, Heagarty, Bullard, and Pivchik (1968) found the majority of their sample of 40 FTT children "were members of intact, relatively stable families with steady incomes" (p.695). They cautioned against consistently assigning blame for the growth failure to poverty or any other specific entity.

Homes were often disorganized, with no set routine to give stability and structure to the child's life (Casey, Bradley, & Wortham, 1984). One controlled study of a matched sample indicated that mothers of FTT children believed their neighbourhoods to be less friendly than did mothers of children without growth failure (Kotelchuk and Newberger, 1983). The FTT mothers also reported that they were more isolated from extended family members who could provide support.

Instability in the family may be emphasized and exacerbated by frequent moves (Roberts & Maddux, 1982; Oates, 1984). Few extended family members and friends were

available to offer support and assistance (Drotar, 1988; Kotelchuk & Newberger, 1983). The implication of this research is that prior to the introduction of an intervention program, assessments of the child, the caretaker/family unit, and the child/caretaker interaction and functioning should be undertaken.

Parent/Child Interaction

Attachment, defined as the "enduring affectional tie that one person forms to another specific individual", is a critical developmental issue between a child and a parent during the first year of an infant's life (Kemp & Page, 1987, p.179). The species-specific response patterns, through which attachment develops, are the result of parent/child interactions over time.

The type of response the parent makes to the child may depend on several factors. If the pregnancy were difficult and of high risk, the mother may be afraid to allow herself to begin the process of attaching to the child prenatally (Kemp & Page, 1987). The forced separation that may occur if the newborn is premature or has developmental problems compromises the mother's ability to respond to the child. The parent's perception of whether the child is difficult to caretake in any of the following areas: crying, feeding, spitting up/vomiting, sleeping, and bowel movements, is instrumental to whether attachment occurs (Affleck, Allen, McGrade, & McQueeney, 1982).

Ayoub and Milner (1985) suggest that the feeding situation and the interactional process between parent and child are the best indicators of a problem resulting in FTT, and of any improvement due to intervention. Mothers of FTT infants have demonstrated deficits on several dimensions in interactive behaviour that have been suggested to facilitate development and security of attachment in normal children (Bradley, Casey & Wortham, 1984; Pollitt, Eichler, & Chan, 1975; Drotar, 1988; Drotar, Eckerle, Pollotta & Wyatt,

1990). Clinical practitioners must be cognizant of what to observe and of how to interpret their observations of the mother/parent/child interaction. Casey, Bradley and Wortham (1984) recommend that attention should focus on the verbal and affective responsiveness between the parent and the child.

Stressors. As open systems, all persons are affected by what happens in the environment around them, both immediate and far afield, concurrently with what is happening within themselves (Fawcett, 1975). Any occurrence that exerts pressure or strain on the individual may be considered a stressor. The capacity of an individual for tolerating the stressor may have a positive or negative impact on his/her life (Altemeier, O'Connor, Sherrod, Yaeger, & Vietze, 1985).

Physical factors that may affect the fetus are: maternal cigarette smoking during gestation, prematurity, maternal alcohol intake, genetic factors such as autosomal recessive disorders, and maternal malnutrition (Bithoney & Dubowitz, 1985). These factors alone may not be sufficient to cause FTT but act in conjunction with other psychosocial problems to the child's detriment.

Besides the disorganized and isolated homes, parents of FTT children were found to have major disputes with their few friends (Edgeland & Farber, 1984). The death of a friend has a significant impact on any person. For someone who has few friends, the death of such a person has an even greater stressful impact (Altemeier, O'Connor, Sherrod, & Vietze, 1985). Stresses on the mother/parents then affect the ability to relate to their child. Children who are malnourished are prone to frequent mild infections such as otitis media and gastroenteritis (Bithoney & Dubowitz, 1985; Frank, 1985; Sherrod, O'Connor, Vietze & Altemeier, 1985). Hospitalizations resulting in separation for the mother/parents and child serve to further damage an already fragile relationship. These physical stresses on the child add psychological stress to the mother/parents who already see themselves as incompetent

caretakers. Health care professionals must be able to assess the supports that would counteract these stresses and determine what is available in the family's environment.

Supports. The availability of significant others, whether family or friends, on whom the mother/parents can rely is of prime importance (Newberger, Hampton, Marx & White, 1986). They then feel less isolated and feel that someone cares what happens to them. For the child, the presence of one stable continuous relationship, be it an older sibling, grandparent, aunt, or neighbour, can have a positive effect on the child's development (Werner, 1983).

Professional caregivers who provide nurture and education to the parent can serve as major supports. Parent aides in the home can guide and role model care for the child, always encouraging and praising the mother/parents in their efforts. There has been little research on the effect that supports in the home have on the child's growth and development. This factor was considered in this pilot study.

Long Term Effects

There has been limited research into the long term effects of FTT in childhood. English (1979) noted that there have been no studies of adults who had suffered from FTT to determine what effects, if any, lasted into adulthood. Goldbloom (1982) found that catch up growth had occurred in his study sample but behavioral disorders, educational difficulties and intellectual impairment persisted in those with FTT. This finding was in contrast to that of a study by Mitchell, Gorrell and Greenberg (1980) wherein children continued to suffer deficits in weight gain although their lengths were unaffected. Prognosis was decidedly poor in another study sample, with 40% continuing to suffer from physical problems (Glaser, Heagarty, Bullard & Pivchik, 1968).

Intellectual functioning remained delayed in more than 50% of those studied by

Elmer, Gregg, and Ellison (1969), with growth delay and behaviour disorders common to this group. The longest follow up study noted to date was undertaken in Australia where children were assessed up to 12.5 years following initial diagnosis of FTT (Hufton & Oates, 1977; Oates, 1985; Oates, Peacock & Forrest, 1984; 1985). The researchers found the children had a height age or weight age one or more years below their actual age. The children in this study had lower ambitions and higher levels of antisocial behaviour than the comparison children. The families where children failed to thrive had mothers who offered little verbal stimulation and showed less interest in the child's school performance than comparison mothers or mothers in families where children were abused. In addition, there was an increased risk of abuse to FTT children increasing the potential for removal of the children from the home by child welfare authorities (Creighton, 1985; Skuse, 1985).

Early malnutrition resulted in deficits in motor skills and in intelligence quotient (IQ) in follow-up studies 4-10 years post diagnosis (Galler, Ramsey, & Solimano, 1985; Galler, Ramsey, Solimano, Lowell, & Mason, 1983). With current socioeconomic status and family functioning controlled the physical insult to the children continued to present long term negative sequelae. The costs to society in the loss in human potential, because of the range of physical, medical, and psychological functions that can be impaired in children who fail to thrive, cannot be calculated. The consequent long term negative impact of FTT in children who are unable to reach their full potential in life because of behavioral and learning difficulties are a sad legacy of the syndrome (Bithoney & Rathbun, 1983; Hufton & Oates, 1977; Oates, Peacock & Forrest, 1985). The economic costs to the health care system for hospitalization and diagnostic testing are a drain on the system (Drotar, 1988).

Diagnosis and Intervention

Assessment

Ayoub and Milner (1985) suggested that the interactional process between the parent and child may be studied during a feeding session for indicators of attachment disorders. The species specific response patterns, through which attachment develops, are the result of parent/child interactions over time (Kemp & Page, 1987). The parent's perceptions of whether the child is difficult to caretake is instrumental in determining whether attachment occurs (Affleck, Allen, McGrade, & McQueeney, 1982).

On diagnosis of a FTT child, a thorough medical history and physical examination should first be conducted to indicate which further tests, if any, should be performed (Goldbloom, 1982; Sills, 1978). Berwick, Levy and Kleinerman (1982), Roberts and Maddux (1982) and Sills (1978) noted that extensive diagnostic testing revealed little additional information that the physical and psychosocial assessments had not already indicated. Kempe and Goldbloom (1987) stated that unless the history and physical examination strongly suggest an underlying disease, all diagnostic testing should be withheld for 7-10 days while a trial period of observation and feeding and nurturing of the child is conducted. Hospitalization for a period of two weeks has been recommended by some researchers to allow for assessment and nutritional treatment (Drotar, 1988; Drotar, Eckerle, Satola, Pollotta & Wyatt, 1990).

A developmental assessment which is part of the initial evaluation can be used as a baseline against which the response to treatment can be measured (Goldbloom, 1982; Kempe & Goldbloom, 1987). When a coordinated multidisciplinary team is available and children are not at risk for further deterioration in their physical condition outpatient assessment and intervention may be effective (Schmitt & Mauro, 1989).

A detailed assessment of the feeding habits of a FTT child, the actual caloric intake, distress in feeding, the mother/child interaction, and schedules for feeding is necessary before intervention planning may be initiated (Fosson & Wilson, 1987; Linscheid & Rasnake, 1985; Stephanson, 1980). A home visit may be needed to provide an accurate picture of family functioning and interactions (Drotar, 1988). Skuse (1985) suggested that the reliability of observations are enhanced by repeating them in various settings.

Intervention Strategies

Altemeier, O'Connor, Sherrod, Yeager, and Veitze, (1985) suggested that listening effectively and providing support are the most salient points in the attempt to assist the families of FTT children. The complex etiology of FTT requires a team approach to assessment and intervention (English, 1979; Peterson, Washington & Rathbun, 1984). A comprehensive assessment of medical, nutritional, psychosocial and developmental issues may include consulting agencies and professionals outside the hospital, such as day care services and family service agencies. Prior to intervention the assessment phase must allow for the establishment of trust of the professionals by those distrustful of the 'helping' professions (Lerner & Bergan, 1986).

Coordination of the multiple workers involved is required to avoid an overlap of services provided, or worse yet, the omission of any intervention in the child's/family's problems (Drotar, 1988; Hathaway, 1989). FTT presents such a frustrating and difficult problem that many professionals would rather avoid working with these families (Drotar et al, 1985). Fletcher (1982) cautioned that anxiety, mistrust, competitiveness, and anger are emotional reactions that professionals working with these demanding problems often experience. Unless professionals provide a nurturing environment for each other, developed on a shared frame of reference used for assessment and management of the cases, they may

respond with inappropriate and sometimes destructive actions toward one another. Realistic expectations of the families and of the workers, based on shared knowledge of the limitations of skills, knowledge, and legal options available to each, are necessary for effective participation within a team.

In a case study, Mira and Cairns (1981) found that the mother/primary caretaker required a simple, direct and explicit program that taught only a few interactive behaviours. The addition of various uncoordinated efforts at intervention may lead to confusion for the families (Berkowitz, 1985; Drotar, 1988). The tendency of mothers of FTT infants to concrete thinking suggests that an active, practical and supportive approach to treatment would be more effective than a problem-solving, psycho-therapeutic approach (Oates, 1984). This intervention should persist for a prolonged period with a minimum of two years (Oates, 1985; Steele, 1986; Yoos, 1984).

In a review of the charts of FTT children for one year at one large center, Thomlinson (1987) found a lack of the focused multidisciplinary intervention which is necessary because of the complexity of this syndrome. The sparse documentation showed that any long term follow-up of the children was lacking. Furthermore, a survey of all major paediatric facilities in Canada failed to produce any coordinated assessment and intervention plans or guidelines from any of the ten centres (Thomlinson, 1987).

The length of time the child has been failing to thrive and the velocity of weight gain are greater predictors of the success of the intervention than the characteristics of the child's environment (Sturm & Drotar, 1989). Individual differences were substantial in children with FTT. In Sturm and Drotar's study, some children developed significant nutritional deficits as pre-schoolers, underscoring the need for close monitoring of growth and nutritional status following hospitalization for FTT. It is imperative that the child's caloric intake be increased beyond that usually required for the age because malnourished

children develop an elevated metabolic rate (Krieger, 1974). This is indicative of the predominance of metabolically active tissues in children who have lost adipose tissue and muscle mass.

An initial admission to hospital may be necessary to allow diagnostic and assessment time. This admission may serve to interrupt a maladaptive mother/child relationship and permit intervention strategies to be introduced. One other major advantage to admission is the opportunity to role model positive interactions for the child/mother/parents and to provide successful feeding interactions that could then continue at home (Larson, Ayllon, & Barrett, 1987).

It is extremely important that practitioners be cognizant of the impact of parent-practitioner conflict (personal communication, D. Drotar, June 1988). Potential effects when parents are informed of the diagnosis of FTT are:

Mutual Frustration

Maladaptive Practitioner Behaviour

Discrediting parental ideas
 Arguing with parents
 Parents are labelled as emotionally disturbed
 Avoiding parents
 Premature recommendations to terminate parental custody



Maladaptive Parental Behaviour

Increased anger/arguing with staff
 Avoidance of physician
 Not visiting child
 Signing child out of hospital
 Doctor shopping
 Non-compliance with treatment recommendations

(Handout, D. Drotar June, 1988)

Although many resources are available to help FTT child/mother/family units, the lack of coordinated programming may lead to duplication and/or gaps in service delivery. Positive results are visible only after much time and effort, therefore, professionals become frustrated from being unable to promote changes in the unit (Copans, Gundy, Rogan, & Field, 1979; Drotar, 1988).

Several relevant significant observations regarding the use of multidisciplinary teams have been noted. Lerner and Bergan (1986) noted that the results of working with multiproblem families are difficult to quantify. Drotar emphasized the paucity of studies on the effects of implementation of multidisciplinary team approaches to intervention in FTT (personal communication, June 1988, Cleveland, Ohio).

A coordinated program would allow for the development of an intervention plan based on the needs of the family unit as identified by both the mother/family and the health care personnel involved. Mutual support and interaction of both the family and professionals provides for enhanced service delivery and the prevention and diffusion of stressful situations and contribute to a potential reduction in abused children.

CHAPTER IV

METHODOLOGY

The lack of any consistent long-term program delivery for children with environmentally based or nonorganic FTT was noted by both the researcher and by professionals at The Child Protection Centre at the Children's Hospital in Winnipeg, Manitoba. Children who suffer from organically based FTT receive coordinated care from physicians, nurses, child life therapists, and social workers since specific clinics exist for children with such conditions as cystic fibrosis, cardiac anomalies, haemophilia, and various physical handicaps.

In a study of 59 admissions for FTT between 1985-1986, the researcher found a diagnosis of organically based FTT for 19 children and a nonorganic or a combined etiology for 40 cases. There was no evidence of any concerted attempt to provide long term service delivery to the children who were diagnosed as failing to thrive because of environmental reasons.

An integrated program of assessment, planning and long term follow-up for FTT children was developed by the researcher in conjunction with other professionals with experience in the field. This program was pilot tested at a tertiary care paediatric facility. This pilot included the involvement of members of a number of disciplines to provide the child/mother/family unit with support and assistance in the areas of need, as identified by both the clients and involved professionals. The child's physical and emotional needs, the home situation, and the available supports for the primary caretaker determined what resources were required.

The implementation of this coordinated program was evaluated by:

- a) studying the effects the multiple service delivery had on the growth and development of the child, and
- b) determining whether the intervention, as delivered, contained the elements the mother/family and the professionals involved considered necessary.

Design of the Study

During the study the researcher examined the implementation of a coordinated multidisciplinary program to guide case finding and intervention with FTT children. An action research framework was used to measure and control a change in current practice through objective methods (Kappeli, 1988). In response to an identified need, the program was developed by practitioners with knowledge and clinical expertise in the field, employing present scientific and theoretical knowledge (Argyris, 1982). Strengths and inadequacies in the intervention were highlighted during the research thus allowing for necessary changes before the introduction of a full scale program. A pilot study was chosen to provide information about the particular application of the program. Subjects, method of operation, and measures were tested to allow for refinement before further research may be conducted as suggested by Prescott & Soeken (1989).

Client input was a prime requisite in all phases of the program, including initial assessments, ongoing care, and evaluation of the program. Close collaboration between researcher, clients, and professionals was necessary to produce consensus on the desired outcomes (Susman & Evered, 1978). The goal of this research was to produce knowledge in the service of action which would then serve as a guide for learning and modelling of behaviour in similar situations in the future.

Sample

The sample for this study included all children diagnosed as FTT for other than strictly physical causes, admitted to the referral hospital during a seven month period, whose mothers/caretakers and physicians agreed to participate in the pilot program. Additional inclusion criteria were:

- 1) the mother/primary caretaker had to be English speaking or an interpreter had to be available, and
- 2) the family lived within a two hour driving radius of Winnipeg.

It was expected that this convenience sample would include 10 families as participants. Of the 54 children discharged from Children's Hospital with a diagnosis of FTT between April 1 and October 31, 1989 five families participated in the study. In several cases the children were discharged after an admission of one to two days and the physicians did not agree to referral to the study. There were children from outside the two hour driving limit who were admitted to hospital during that period as well.

Children whose FTT resulted from an organic cause, such as hydrocephaly, congenital renal or cardiac disease, and/or metabolic disease, were excluded from the study. The FTT was discussed with the paediatrician prior to determining inclusion or exclusion. Several children for whom organic causes were suspected were not referred to the researcher by the physicians and/or nursing staff.

Ethical considerations

As in all nursing research projects, the ethical implications of a study designed to intervene in the lives of children who are failing to thrive and their families needed careful consideration. Not only were the environmental conditions in which the FTT had occurred being studied and analyzed but interventions were planned and implemented. This meant an

involvement of the coordinator/researcher in the lives of the families who had agreed to participate.

Before data collection began, approval was obtained from the Ethical Review Committee of the School of Nursing of The University of Manitoba. Permission for access to patients was requested at the paediatric referral hospital in Winnipeg through the Paediatric Research Coordinating Committee (See Appendix A).

Confidentiality of persons involved in the intervention program did not differ from the legal confidentiality that exists in medical care, because the professionals involved had to be aware of the participants identity in order to provide service delivery. The children's names were coded and did not appear on any of the research files. This coded information was kept under lock and key by the researcher.

At all times the rights of the child/mother/family were paramount. For involvement in the program, a signed consent from the mother/legal guardian was obtained after she/he received an explanation of the program. The mother/caretaker had the right to withdraw the child from the program at any time with no detrimental effects to the care being received. However, when it became apparent during the course of the research project that problems existed within the family unit that were beyond the scope of the program, as originally designed, the therapeutic imperative took precedence over any research goals. This meant that, when it was evident that parental assistance was not forthcoming voluntarily and the child's condition was a cause for concern, the Child and Family Services Act, Manitoba (March, 1986) was followed and the assistance of Child and Family Services was sought.

Recruitment

As the children remained under the care of their primary physicians, access to the subjects was through physician and nursing staff referrals. The Medical Director of the

facility was apprised of the study and assistance sought to approach the paediatricians practising at the facility. The physicians were familiarized with the study in a letter from the Medical Director in the Paediatric newsletter that is distributed regularly to the paediatricians in the department.

A staff education program regarding the signs and symptoms of FTT, child and family characteristics, recommended treatment, and long-term negative sequelae that result from lack of treatment of this syndrome, was instituted on the units to which children who are failing to thrive are admitted. Articles on FTT and a written explanation of the program (See Appendix B) were provided on each unit. Information sessions were held for head nurses, staff nurses, the ambulatory care staff, child life, social workers and the staff of the Services to Native Patients. These sessions were conducted over a period of two months, in various localities and at times suggested as convenient by the head nurses, to allow staff attendance. Senior residents were informed of the study and, as staff rotated to other services, additional sessions were held.

The patient census was monitored daily, by a nurse of the Child Protection Centre, for admission of a FTT child. The researcher visited the medical units of the facility daily to remind staff of the study. If the physician determined that the child met the criteria of, and was appropriate for the study, either the physician or nursing staff presented the mother/caretaker with a written explanation of the program (See Appendix C). Once permission had been received, the mother/primary caretaker was visited by the researcher and invited to participate in the study (See Appendix D). In two of the cases there was direct referral from the paediatrician caring for the child prior to admission to the hospital.

A consent form agreeing to participation was signed by the mother or legal guardian for the child (See Appendix E). Both the explanation to the mother/caretaker and the consent included a request for potential publication emphasizing that names and specific

personal information would not be used.

Data Collection

Upon referral to the program and agreement to participate the mother/caretaker was asked to provide demographic information regarding the child/family unit. The mother/caretakers were interviewed at various times post discharge for her/their opinion of what should be retained, added, or deleted from the program (See Appendix F). Although the original proposal included interviews at two weeks post discharge and monthly to three months, this was altered as determined necessary to provide the individualized care needed by each family. For three of the five families the data collection extended over 7-8 months. For the two other families data collection extended over 4-5 months.

Involved professionals were asked their opinions regarding the effectiveness of the coordinated intervention, the impact on their particular discipline, and any suggested changes to the program (See Appendix G). These interviews were conducted with staff who had a major involvement with the family, both from within the hospital and in the community.

Height and weight, which are the chief indicators of FTT, were monitored throughout admission to hospital and during visits to the physician. These were plotted on the National Center for Health Statistics (NCHS) growth percentile charts which show the child's ranking relative to contemporary American children for the same age and sex (Hamill, Drizd, Johnson, Reed, Roche, & Moore, 1979) (See Appendix H). These standards, based on data from over 20,000 subjects, are accepted in both Canada and the United States.

The standardized Yale (Gesell) Development Tests are tests of motor, adaptive, language, and personal-social skills (Ames, Gillespie, Haines, & Ilg, 1979). The results are expressed as a developmental quotient (DQ) which presents the child's development in

comparison with peer norms. Trained professionals use these tests to obtain qualitative information and quantitative data of an ordinal level. These tests provide specific data as to the child's developmental profile from four weeks to six years of age. Validation of the test as defined by over and under screening, indicated there were no false negatives. All "abnormal and questionable children" were detected while the "false-positive overreferral rate was 5%" (Knoblauch, Stevens, & Malone, 1980, p.201).

Interobserver reliability for behaviour patterns was 93.7% agreement on 2302 comparisons. Interrater reliability for assigning maturity age levels, as calculated for 184 cases, ranged from .84 to .99 (Knoblauch, Stevens, & Malone, 1980). In this study, testing by Child Development personnel was conducted as soon after admission to hospital as possible for those children for whom their paediatricians deemed necessary. Follow-up testing as decided by the development clinic physicians was determined according to the children's needs. Further testing beyond this time will be dependent on need, as evaluated by the paediatricians at the Child Development Clinic based on the progress shown by the children.

Families were interviewed to determine the benefits or negative impact they believed had occurred as a result of involvement in the program. Medical and nursing staff who had cared for the FTT children were also interviewed to further determine how the care of these children progressed. Open-ended interviews allowed for the inclusion of any factors that the professionals and family units believed relevant to the program. These descriptions documented aspects of the situations which require inclusion in the program, a change in the program and/or reeducation of the professionals (Argyris, Putnam, & Smith, 1985). Triangulation of qualitative and quantitative methodologies in the proposed research were used to ascertain if there was convergence in the results of the introduction of the intervention program.

Data Analysis

The analysis of the height and weight changes of the FTT children on admission, as compared to end month testing, was by paired comparison procedures. The effect of the nursing intervention was determined by the clinical significance of the differences between the pretest and posttest mean scores. This within-subjects pretest and posttest design used the prescore and postscore of each child in the sample. Pretest and posttest scoring of developmental stages in weeks gained as defined on the Yale tests was analyzed by the same means for the children requiring developmental testing. Because the children acted as their own controls, reliance for any statistical significance is on the comparison of values from before the intervention to those after the intervention (Wilson, 1985). Because of the small size of the sample population in the pilot study statistical analysis and generalizability of the results is limited.

Changes in the children's growth were considered clinically significant if there was weight and height gains for the children. Improvements in both these parameters are usually detectable only over a more extensive period of time. Glaser, Heagarty, Bullard, and Pivchik (1968) found that at eighteen months 40% of their sample continued to show slow physical growth. Quantitative increases in DQ and qualitative increases in behaviour, as determined by the developmental paediatrician, are considered clinically significant.

A review of the program in relation to each case of FTT provided the researcher and the involved clinicians with the data required to decide the strengths of the intervention and to alter any identified inadequacies. By tracking the numbers of spontaneous invitations to mothers/caretakers to participate initiated by physicians and nurses, the researcher was able to determine whether further educational programming for staff was required in the hospital. Professionals were able to review any service gaps or redundancies to reformulate means of care delivery. Mothers/families had input into the types and methods of assistance

available to them. The total intervention was thus evaluated and modified in the light of ongoing knowledge of what worked and what did not work.

The actual home life experiences of the children in the study, and of their families, provided the background on which the individualized intervention programs were based. There are similar experiences in the lives of all the children and their caretakers, but the impact of the stressors and of the supports create a unique aggregate for each of the family units. It is this uniqueness that forces professionals who attempt to assist clients and patients to tailor basic programs to provide optimum benefits for child and family unit.

In the analysis of the methods of implementation of the proposed program and, the evaluation of its effectiveness, it is imperative the researcher provides a comprehensive data base for the rationale why specific interventions were instituted. Individual case studies (see Appendices I to M) offer a glimpse of the circumstances surrounding each family.

PART II

FINDINGS

CHAPTER V

AT INTAKE

The Children

Recruitment

Five children with a diagnosis of FTT and their families were recruited into the study from 54 admitted into Children's Hospital, a tertiary care paediatric facility during a six month intake period. The reasons children with an admitting diagnosis of FTT were not recruited into the study were:

- a) they lived beyond the 2 hour driving limit,
- b) the child's FTT was due to organic causes and the family were involved with multiple supports,
- c) several physicians did not wish the parents to be contacted about the study,
- d) two parents/guardians refused involvement in the study,
- e) the researcher was not informed of the admission of the child until discharge,
- f) the child was discharged prior to the opportunity to speak to the parent, and
- g) children did not meet the anthropometric criteria.

Anthropometric Criteria

The children who were admitted to the study ranged in age from 5 months to 37

months. Their FTT had extended from periods of two to three months to a general FTT of two years duration. All of the children met the criteria of weight below the 5th percentile on the National Center for Health Statistics percentile charts (see Appendix H). Two of the children had decreased two percentile lines in the previous two months while three of the children had been suffering from growth failure over a more extensive period of time. Their FTT had resulted in reduction in their height to below the 5th percentile as well, demonstrating the chronic nature of their FTT (see Table 1).

For two of the latter children the decrease in head circumference to below the 5th percentile provided evidence of the extreme severity of their growth failure. The malnutrition from which they were suffering had resulted in tissue depletion, suggesting nutrient intake sufficient only to maintain vital functions.

Of this sample:

- 1) 2 children were suffering decreased weight while their heights and head circumference measurements remained within normal limits, indicating acute or recent malnutrition,
- 2) 1 child exhibited weight and height reduction with a head circumference within normal range, demonstrating chronic malnutrition, and
- 3) 2 children suffered from drastic reductions in all three measurements, signifying severe malnutrition. A sibling of one of these latter two also was below the 5th percentile for weight, at the 5th percentile for height, and above the 5th for head circumference, warning of impending problems for this child as well.

TABLE 1 - Demographic variables of FTT children and their families.

Children	1	2	3	4	5
Sex	M	F	M	M	F
Age (months)	16	6	20	37	14
Weight	9.04 kg	4.575 kg	7.85 kg	11.7 kg	7.86 kg
Weight %	< 5%	< 5%	+ < 5%	+ < 5%	< 5%
Height	78 cm	60 cm	76 cm	90 cm	70 cm
Height %	10%	5%	< 5%	< 5%	< 5%
Head Cir.	47 cm	40.5 cm	46 cm	49.5 cm	42 cm
H.C. perc.	5%	25%	< 5%	< 5%	+ < 5%
Parents	2	2	1	1	2
Income Assist	0	0	Yes	Yes	Yes
Working	2	1	0	0	0
Accommodations	Rental	Rental	Rental	Rental	Rental
Siblings	None at intake 2 later	0	2 1 Sibling FTT	0	0

Physical and Behavioral Indicators

All of the children were emaciated with little subcutaneous fat, while four displayed decreased muscle mass. Four of the five suffered from muscle wasting with loose folds of skin at the buttocks. Their arms and legs were extremely thin and spindly. The fifth child who was 37 months old did not exhibit any depleted muscle mass. This child was petite in stature and physical build but demonstrated no muscle wasting; in fact, this child had very smooth skin texture.

Four of the children were pale with little colour in their cheeks. Their eyes appeared "large for their faces" giving the children the appearance that they were staring at the world. Two of the children's faces were disquietingly expressionless; a blank appearance presenting to the world.

Three of the children were listless with decreased body activity. They remained quiet and used a minimal amount of energy in any activity. They would remain quiet, both when they were held and in their cribs. Child #2 maintained flexed hips and knees with the arms held out to the side, flexed at the elbows. Child #3 would turn away from staff who attempted to attract his attention and was content to pick up and put down toys that had been placed in the crib.

In contrast to expectations, two of the other children were active, one to the point of never remaining still. This latter child only ceased movement when he was sleeping which again, contrary to findings in the literature, was peaceful and not disturbed. The two most severely affected children had expressionless facies while they silently watched activities around them. On admission these two children did not smile or respond to staff attempts to make them laugh. They did 'whine' and display signs of irritability but did not formulate any sounds and did not say any words.

The two who showed only weight loss discriminated between staff and their mothers

who remained in hospital throughout their admissions. These mothers provided complete care for their children, accepting limited assistance from nursing staff. They slept in the children's rooms and ate in the hospital cafeteria with the children with them.

The two most affected children did not discriminate between staff and their mothers/parents and would allow any person to pick them up and cuddle them. They exhibited no evidence of stranger anxiety. Even when their caretakers were present these children were willing and ready to have anyone available pick them up and walk out of sight of the parents. When they were picked up by any staff member on the units they would snuggle into the holders' arms and be content to be held. This indiscriminate behaviour signified that the children had not formed attachments with their primary caretakers; an indication that maladaptive attachment patterns had occurred.

The third child displayed mild stranger anxiety but was willing to allow others to talk to him and/or pick him up. This child however, was constantly "on the go" and would laugh and run away, teasing staff who attempted to catch him. His speech consisted of "parroting" sounds and words of anyone who spoke to him. He was able to verbalize some requests, but in sentences of no more than three words. This child was able to discriminate between his mother and staff members in the hospital. He appeared to take great delight in running a circular loop around the ward with his mother 'in hot pursuit'.

Two of the five children had previous admissions for FTT. One had been admitted at eight months of age to another hospital, at which time an intervention involving several agencies had been developed. The other child had been in hospital at three months of age and was now being followed regularly by a paediatrician and a public health nurse. Although the remaining three children had regular ongoing contact with their family practitioners or paediatricians there had been no intimation that a problem existed prior to the admission.

Reasons for Admission

The reasons for admission on this occasion were:

- 1) Child #1's weight loss over two percentile lines in the past three months - a concern of the paediatrician and the parents,
- 2) The mother frequently brought child #2 to the paediatrician's office stating the child was sick with "stomach trouble". The weight loss of the past two months was worrisome to the physician and the public health nurse.
- 3) Child #3, who had a previous admission for FTT, was seen for developmental testing and the physical condition prompted the physician to contact the child welfare worker, the family paediatrician and this researcher to seek admission of the child for in-depth investigation of the problem.
- 4) The mother had originally taken child #4 to another clinic but, upon moving to the area, had begun using the outpatient clinic of the hospital. She asked the paediatrician to find out why the child was not growing as he should. The mother commented to the researcher prior to admission to hospital for investigation "Look at him ... does he look like a normal three year old to you?". This child's physical growth was the mother's reason for concern. Although this three year old's speech was limited and he had not been toilet trained, these factors did not trouble the mother as much as his growth failure.
5. The parents brought child #5 to the emergency clinic on several occasions because the child was refusing to eat. The family physician had not discussed the apparent growth failure with the parents. When the paediatrician from emergency clinic suggested investigation the parents chose to switch to this paediatrician.

In the available maternal histories there were no notations of any abnormalities during any of the pregnancies. For all the children apgar ratings were 8-10 at one minute,

and 9-10 at 5 minutes. There was no indication that any problems had been experienced during the deliveries. Two of the children were breast fed while the other three were bottle fed from birth. From the postnatal notes that were available, there was no indication of eating or health problems in the immediate postnatal period.

Two of the children had no siblings; one had a twin and a sibling two years older; one had no siblings at intake but twin siblings prior to the end of contact; and one had a step sibling from both the mother and the father from previous marriages. One mother had originally considered surrendering her child for adoption but decided against this course of action within a documented five days of delivery. There was a notation on the postnatal chart of one other child that the mother had not prepared any clothing (no layette) for this child to use on discharge from hospital. Income security had provided assistance to the mother to purchase these items following delivery.

The Mothers/Parents/Caretakers

Characteristics

Two of the five children lived in single parent families where the fathers did not contribute to child care, neither financially nor physically. In one of these families the father had on occasion taken the child to visit his own mother. In the other family the father had no contact with the children following separation when the twins were four months of age.

Although three of the fathers were in the home they were not contributing substantially toward the physical care of the child or had in the past been absent from the family. As one of the mothers commented "when my husband comes home from work he eats his supper and then he reads his books". One set of parents had been separated for several months, during which time the mother had been the sole caretaker, but had

reconciled three months prior to admission of the child to hospital.

The mothers ranged in age from 22 to 36 years while the fathers were slightly older. All but one of the families had extended family within the city of residence. The maternal grandparents of one of the children had regular contact with the family, taking the older sibling to their home most weekends. Although the maternal grandmother of one of the children lived in the city, she did not regularly see or assist with the child as there was tension expressed between the father and this mother-in-law. On a regular, but infrequent basis, one mother took her child to visit both sets of grandparents and great-grandparents despite the fact that the father provided no care for the child. She noted that "...it would not be fair to the child if he could not see his grandparents".

One family had immigrated to Canada from Southeast Asia within the past five years and did not have any family living in this province. They had also moved from another city where they had spent several years. That move had been prompted by the father's work. This father was apprenticing at a trade and attended school for several months each year.

Two of the five children had one or both parents working. One mother worked full-time until the birth of the siblings and intended to return to work following her maternity leave. The other mother worked until the birth of the baby and had not returned to work, but frequently expressed the desire to do so. She had a friend who was interested in babysitting for her but the husband did not agree with her wishes.

Three of the families received their support from income security. The parents of the two most severely affected children received biweekly support, indicating previous budgeting difficulties that warranted close follow up by the income security workers. In one of these families each parent received separate assistance because of they had separated on several occasions. All three families received provincial assistance because they were

considered in need of long-term support. Families requiring short term assistance receive this from the city welfare office.

Regardless of the fact that extended families were present within the city, none of the mothers had many family members or friends with whom they associated. Being alone was a characteristic common to all of these mothers. The one mother who was working did socialize to a limited extent with the staff with whom she worked. She also had a small circle of friends extending from grammar school days. The past suicide of one of her friends had been particularly devastating to this mother as she felt guilty that she had not been aware of the friend's "cries for help". Over the past several years, the visits with this friend had been limited by the fact that both were involved with family obligations but this only added to this mother's feelings that "perhaps I could have done more to prevent it (the suicide) from happening".

Four of the mothers had difficulty speaking about their childhood. The mother who had immigrated would start to cry when she talked about the family she had left in her home country, but she continued to initiate conversations describing her former life, her parents, and her siblings with both the public health nurse and the researcher. One of the mothers, who was open and willing to discuss her present circumstances with the professionals, was not able to discuss her childhood. When asked a question about what "growing up had been like" she would give a vague response or resort to platitudes.

One of the mothers was very angry at the professionals who "were ruining her life by all their interfering". This mother condemned the 'system' for the problems she was having. On many occasions she bitterly stated that, if everyone would just leave her alone, she and her children would be all right. A second mother, over the extended admission, did not visit for periods up to a week but would telephone to ask about the child's progress. This mother stated that she was tired of coming to the hospital so often and

wanted the child discharged. However, she did not precipitate discharge and was persuaded to leave the child in hospital until considered medically fit for discharge.

Family Relationships

Severe marital strain existed in the two-parent families. Conflict and anger was expressed by each spouse on various occasions, except in the one family where the father would retire to his room when the researcher visited. This father was courteous and polite to the researcher on meeting and then would withdraw from the visit. The wife in that family expressed great anger that her husband would not allow her to socialize with her friends nor would he allow them to visit. She commented on each visit that her husband offered no help with the child.

One of the mothers had told her common-law husband to leave when she found out that he was sleeping with other women. She spoke with derision in her voice when she noted that "he got his girlfriend pregnant and then he took off". When the researcher asked if this girlfriend was receiving any financial assistance from him this mother said "nothing at all. He would not even buy his son a toothbrush when I asked".

All families lived in rented accommodations throughout the city, with no specific area identified. Two families moved to larger units within the same complexes during the course of the study. The mother of one of the most severely affected children had moved to a completely different section of the city, away from the area where her parents lived. The other two families had leases that would not terminate until later in 1990. One mother was hoping to find a bigger apartment before her lease expired as she and her child shared the bedroom. She intended to seek accommodation within the same area as the location is convenient to the child's daycare, the hospital, and shopping.

Two of the families owned cars which the fathers used to commute to work. The

other three depended on public transportation for travel. During the extremely cold weather of November and December 1989 this lack of transportation served to isolate the child(ren)/caretaker within the home. Only two of the families knew any of their neighbours in their housing complexes. One child was baby-sat by a neighbour father who was caring for his own infant while his wife worked. The other families did not have friends or family within their apartment buildings with whom they associated.

Parent/Child Interaction

One of the mothers was content to allow her child to run about and play as he chose, setting few limits on his activities. She did however, have all harmful materials placed on a high shelf which was not accessible to the child. This mother took delight in her child but was not knowledgeable of normal growth and development; therefore she did not know what to expect her child would and should be doing at the appropriate time ranges. This mother took the child to the park to play, read to him a limited amount and during the summer took him on picnics. This child was smiling and laughing much of the time.

One mother believed her child to be ill and would not feed her more than four ounces of milk at one time "she is always throwing up and burps all the time". Explanations that spitting up was a normal exercise for babies made little impact. This mother concurred with one other who did not want their babies "to get fat". Two mothers fed their children without facing them, holding them at a distance from them and not cuddling them. When these mothers held the children on the knees they would often face them away from them.

Two of the children refused to eat both for the parents and for staff. These children would close their lips tightly and not allow any food into their mouths. One would drink

both milk and juices but the other had an average fluid intake of 300 milliliters daily during hospitalization. This latter child continued to lose weight in hospital prompting feedings by nasogastric tube for the period of one week.

Three of the children would eat portions larger than normal for their age. The youngest drank eight ounces at a time and settled to sleep, content and peaceful. The other two ate table food appropriately prepared for their ages and would eat more than was sent on their trays. The nursing staff was required to show caution when feeding these children to prevent overeating and emesis.

At the time of the child's admission to hospital two mothers had presented nursing staff with elaborately detailed menus of what they said the children ate at home. When questioned later one admitted that this was not the usual diet at home but continued to maintain that the child ate well. This, in fact, was shown to be true because the child's intake remained high throughout admission, and following, with no perceptible weight gain. The second mother maintained that this was an accurate intake. The child however quickly gained weight in hospital denying any credibility to the mother's assertions.

The mothers of the most severely affected children did not respond to the children's cues for attention and for hunger. The parents would stop feeding the children when they first showed any hint of slowing their intake and would not resume feeding unless encouraged to do so. If the parent wanted to hold the child, regardless of what they were doing at the time, she/he would pick the child up. Response from the parent was not dependent on the child's behaviour and appeared designed to meet the parent's needs at the time, rather than the reverse.

Physical stressors. Three of the mothers smoked approximately a package of cigarettes a day. One of the mothers made up her own cigarettes but the other two purchased theirs. When both parents smoked the drain on their welfare income became

noticeable. All of the mothers denied alcohol abuse during and after their pregnancies.

One mother was four months pregnant when the child was admitted to hospital for investigation. She said that she felt very tired especially after a work day which began at half past six and did not end until after ten. Her child often woke one to two times during the night. A second mother complained of abdominal pain and required medication for a chest infection during the period of the study. A third mother stated that, although she had once been heavier, she now required a liquid diet supplement to maintain her current status. This mother observed that when there was any conflict in the home she stopped eating.

The children received regular medical attention as all of them had suffered some illness. Otitis media was the common complaint requiring medical treatment among the children. As previously stated, two of the children had been hospitalized for FTT during the previous year.

Additional stressors. Two of the mothers were attempting to cope with the stress of raising children as single parents. With no significant other to accept some of the responsibilities for the care of the child(ren) every issue was one to be handled alone.

In the three two-parent families marital discord was openly discussed and readily apparent in conversation. One mother commented that her husband controlled the finances and activities of the family; a factor she resented. In the other two families the relationships were strained and resulted in verbal battles which occurred in the presence of the children. These couples were able to articulate the cause of some of the problems but would not discuss methods of resolution; preferring to change the subject when areas of discord were broached.

Supports. Significant others who could and would share the burden of child rearing were available to a limited extent to these mothers/parents. One mother had a friend who was willing to baby-sit if the mother returned to work. The father in the family would

not, however, take the mother (who was unable to drive) to visit this friend. The family members of the mother who had twin babies during the study time cared for the study child. Some of this family lived outside of Winnipeg which meant they left their own homes to help the parents when they were needed. However, this couple was reluctant to ask for help.

One set of grandparents assisted by buying food to supplement the family diet. This family had the older child visit at their home almost every weekend. The fourth mother visited her family but received no help with caring for the child; nor did she expect any "...I knew that when my baby was born I had him to look after for the next eighteen years". The maternal grandparents of one other child provided an occasional respite for the mother while the paternal grandmother let the family use her car if an urgent need arose. For all of the families, their extended families provided limited support and assistance.

CHAPTER VI

INTERVENTION

Perceptions of Terms

Four of the mothers objected to the term "Failure to Thrive" used as a diagnosis. One commented that she felt badly enough that her child was in hospital, without being labelled a failure. She explained that she did not see the child as failing to grow but rather herself a failure as a mother because he was in hospital as a result of something she was not doing or was doing wrong. Intellectually this mother was able to understand that the complex etiology of FTT precluded pinpointing one factor as the exclusive cause of the FTT. However, she articulated that although she understood this, emotionally it added to "... everything else in my life that had not worked out".

This mother's opinion regarding alternative terms was sought and a discussion held analyzing the impact of the words on her. 'Growth failure' and 'malnutrition' aroused visions of children from third world countries who were starving to death. These terms produced strong feelings of guilt in this mother.

Three other mothers stated they did not like the term FTT and suggested that something less threatening would be more effective. Explanations that this was the Diagnostic and Statistical Manual (DSM III) terminology did not allay the concern. The fifth mother did not comment on the term because, although she had an acceptable command of the language, she commented that she did not understand English well enough.

'Social worker' was the other term that produced fear and anger in the parent(s). As several stated, the only knowledge they had of social work was what they read in the papers or heard from friends or neighbours. The stories they had heard were of workers

"taking" children for little or no reason and they believed that this was the main occupation of social workers. There were suggestions that 'assessment workers' or 'counsellors' would be less threatening terms for the persons involved with the program. All of the parents developed a new perception of the resource role of social workers. Another widely held perception was that all social workers worked for child welfare agencies and several mothers commented that they did not realize the variety of settings that employed social workers.

Hospitalization

Admission. Two of the five children were admitted on a Friday. Although hospitals do not shut their doors on the weekends, diagnostic services are limited to emergencies. Child life and dietary consultations are also not available on weekends. For this reason both mothers said there was little purpose in admitting their children on a Friday. If the families had not been known to the physician and the established growth pattern plotted, emergency admission over the weekend would have been justified in view of the growth failure.

These mothers said that since they had been attending regular appointments they saw little value in a quick admission to "just sit in hospital over the weekend". The physician explained that observation by nursing staff over that period provided him with information he needed to diagnosis the etiology of the FTT. The parents had been told that the children were being admitted for testing and then they spent three days in hospital waiting, in their estimation, for something to happen. These parents stated they thought it far more practical to admit the child on Monday and stay into the next weekend if necessary.

One child was admitted on Friday and discharged on Monday morning. Nurses' observations of the mother's interactions while the child was eating were that the mother was not adequately feeding the child who drank well when nursing staff fed her. The

nurses noted that the mother was not responsive to the child while the baby was drinking her bottle.

The public health nurse had visited the home approximately every two weeks since the previous discharge for FTT. After the child had been discharged a referral was made to the public health nurse to continue visiting the mother/child as she had been doing previously. There were no assessments made of the home situation, of the problems confronting these parents, nor of the types of supports available to the parents. The physician stated that the mother needed to see a psychiatrist and commented that the public health nurse should arrange that someone from mental health services see this mother.

One of the mothers was told her child should be admitted to determine whether a low zinc level was a contributing factor in the FTT. Although the abuse intake worker was involved and attempted to meet with the mother, the focus was on a chemical cause for the FTT. The mother refused to meet with the consulting paediatrician who wanted to discuss possible psychosocial reasons for the FTT. She then stated that no one had been honest with her about the child's admission. The child welfare worker assigned to the case expressed the belief that the professionals were "trying to push the mother too quickly".

Despite the efforts of the consulting paediatrician over the past year to explain the seriousness of the syndrome, the mother told all other professionals that this child welfare worker was the only one who had been honest with her. This, in fact, had the effect of dividing the professionals into two camps; one side sharing the mother's opinion, and the other that disagreed with her view. This drawing of lines prompted the child welfare worker and then the homemaker to proclaim that they were the mother's advocates while other workers in this case stated they were the child's, and thus the family's, advocates. This dichotomy, without some areas of overlap, served to create a service delivery gap wherein the mother then found it advantageous to play one side against the other.

Children's care. While in hospital those children whose parents remained with them continued to receive consistency of caretakers. Although their routines were disrupted, these children had their parents caring for them as they had always done. Those children whose parents visited sporadically did not maintain that consistency.

The disrupted care should have resulted in these latter children actually continuing to fail to thrive, or in an exacerbation of the syndrome. However, this did not happen. Of the two children whose parents visited the least, one put on weight immediately while the other required a longer length of time to start gaining weight. Both of these children, socially and developmentally, progressed rapidly while in hospital. This change was denied by their parents who stated that the children had achieved those milestones previously. These changes, in fact, meant that as parents they were forced to face the fact that others were able to succeed with their children when they could not. This was another failure for parents who had faced other defeats and now could not even raise children "which anyone can do", as one mother noted.

The most consistent persons the children saw on a daily basis, besides the head nurse and/or team leaders, were the child life therapists. These persons would regularly take the children to play in the main playroom and on the outside deck when the weather was favourable. They were able to assess parent/child interaction and to role model interactional behaviour for the parents.

With nursing staff working 12 hour shifts, there was frequent turnover of staff. Clearly defined care plans were necessary to communicate consistency in the ongoing plan of care. The Head Nurses who are on the units daily communicated to the staff the expectations for and progress of the child(ren). In particular, one Head Nurse role modelled techniques for feeding children and for assisting them to settle to sleep with the least possible disturbance.

One mother emphasized that to save the parents confusion, day to day expectations should be the consistent. One morning a nurse told that particular mother that the child should have been weighed prior to eating breakfast. The next morning the mother held the breakfast, asked the staff about weighing the child, and then fed him when no one came after one-half hour. A quick explanation of the use of the scale, or that other procedures were taking precedence that morning, would have prevented the discrepancy in caretaking.

In that particular case, there was no observation of parent/child interaction during feeding, except by the researcher. This mother, who acknowledged that she needed to learn more about child care, noted that she would have benefitted from diet counselling and reassurance from nursing staff in conjunction with what she received from the dietitian. The researcher was unable to ascertain whether her presence, as a nurse known on the unit, allowed the staff to concentrate on other patients. This mother had difficulty setting limits for the child with regard to fluid intake. In contrast, she set limits on other behaviour, such as expecting him not to touch ornaments at home and not to spill food while eating; expectations that were beyond that of a child at this developmental stage.

Extended family and friends. There were few visitors from extended family or friends while these children were in hospital. For family #3 the step grandfather brought the mother and siblings to visit the child once in two weeks. The paternal grandmother of child #4 told the researcher that she had come to visit the child after working the night shift. This entailed a 12 mile bus trip each way as this person did not drive a car. The paternal grandmother spoke to the staff on her one visit during the three month hospitalization of child #5 at which time she commented on the marital discord in the family.

The father of child #5 arrived on the ward with a friend several evenings. On no other occasions were friends noted to have visited either the children or the parents while

the children were in hospital.

Diagnosis of the Problems

Assessment

Medical tests. From the variety of medical tests completed (see Table 2) on each child there were no abnormal findings. All tests fell within normal ranges and therefore, were useful only for demonstrating no physical cause for the children's FTT.

Psychosocial assessment. The homemaker for one of the families stressed a factor, identified by a number of the health care professionals, that until "...you really find out what is going on in that family, and what happened in the past, you can't make the right decisions to help that family". An in-depth assessment about environmental influences, both past and present, originates from an amalgamation of the information from all the persons involved with a family.

When the researcher asked parents #1 to meet with a social worker from the Child Protection Centre for an assessment, this created great anxiety for both parents. The mother noted that the only time one reads about social workers in the paper is when children are apprehended. Because they were aware that the child's slow growth was at least a partial result of discord in the home, the parents were afraid that Child and Family Services would take their child. This perception of the powers of the statutory agency, the mandate of the agencies, and reasons why children may be apprehended, were discussed with the parents.

The social worker, conducting the assessment for this family, was able to determine sources of conflict between the couple. The father was not willing to meet with the worker a second time, but the mother attended one other meeting. This mother could clearly articulate the strengths and stresses in the relationship but acknowledged that she was unable to devote energy at this time to producing change.

TABLE 2 - Developmental assessment and investigational procedures performed during hospitalization

Children	1	2	3	4	5
Developmental Assessment	Yes	No	Yes	Yes	Yes
Repeat Assessment	No	No	Yes	Yes	No
Total Number of Investigational Procedures	3	5	13	7	13
Complete Blood Count	X	X	X		X
Electrolytes		X	X		X
Calcium (Ca)			X	X	
Alkaline Phosphatase			X	X	X
Creatinine			X		X
Urea (Bun)			X		X
Carbon Dioxide (CO ₂)			X	X	
Serum Zinc			X		
(PO ₄) Phosphates			X		
Chromosome Studies					X
Total Protein/Albumin					X
Fragile X				X	
Capillary Gases				X	
Oximetry			X		
Urinalysis	X	X			X
Abd Ultrasound		X			
Bone Age			X	X	X
Barium Swallow	X				
Head Ultrasound					X
Skull X-ray				X	
Stools		X			
Audiometry			X		
Sweat Chlorides				X	X
Metabolic Screen			X	X	X

Family #2 presented a cross cultural perspective that introduced new dynamics into an intervention. Assessment without a thorough comprehension of the language was not possible. After four months of follow up, the researcher approached the Immigrant Women's Association for assistance for this family. A social worker from this family's country then began working with the parents, in particular the mother. A clear need for persons with preparation in family assessment and counselling, along with knowledge of the language and culture, was identified.

Home visits by the assessment social workers and the researcher provided a more comprehensive picture of the family dynamics. Watching a child in his/her familiar surroundings may present a very different view than those presented in a hospital setting. Parents are more relaxed, even with a stranger in their home, because they are in a setting where they have control. Should they so choose they could request the visitors leave or not visit, as did one of the mothers.

Visits to the home and other centres that were used by the children/families, such as day care centres, provided information that could be shared to dispell misconceptions among the professionals. At one team meeting a discussion ensued about the distractions that affect a child in the day care setting. The day care workers, unaware that the others at the meeting did not know the physical environment of their particular day care, did not realize the other workers assumed that the day care consisted of one large room. The researcher was able to provide a description of the setting, with its multiple smaller rooms, that allowed the children to work in more intimate surroundings. In this situation the researcher, having knowledge of the day care, but also being aware of the perceptions of the health care workers, could serve as a bridge between the two services.

The resources, family, and friends available to provide support to the child/parents were identified during the assessment of family dynamics. Family #2 had no family in the

province and rarely met with their few friends who lived in the city. Family #4 interacted regularly with the extended family but did not view these persons as a source of support. The immediate family of mother #3 provided support, particularly for the older child who spent weekends with the grandparents. Family #1 had not asked for assistance but found it was provided when they needed help during the birth of their last children. That extended family very quickly arrived to provide child care when the mother delivered twins six weeks prematurely. Several families said they found it difficult, for reasons undefined, to ask their families for assistance. Extended contact with the families would be necessary before these issues could be addressed more fully.

Appropriate long term care plans could not be devised without the necessary completed assessments. Family #4 had the most thorough evaluation of the child/mother environment and yet after eight months information gaps were identified. Time and human resource constraints affect the ability to compile the necessary information.

The Program

The Children

Weight Gain

The primary goal for intervention was for the children to gain weight to that appropriate for them, as determined by their growth curve from birth. With improved nutrition and weight gain those children whose heights and head circumferences were also affected would then improve in those anthropometric measures as well. All professionals involved required reminding that weight gain was a long term goal and that often little change is effected in less than one year of intervention. Actual weight gain in relation to the percentile of growth on which the child placed at birth was the important parameter.

Child #1. Child #1, age 14 months at intake, gained weight following admission

to hospital to between the 10th and 25th percentiles, levelling at the 10th percentile. His height and head circumference which had never gone below the 10th percentile levelled at that stage. This child continued to control his intake by refusing to eat anything that he did not want.

All manner of inducements to encourage him to eat were unsuccessful, unless he decided that he would eat. Breakfasts in this family were hurried as both parents prepared to go to work. Evening meals often were not shared times when all ate together or were forums where problems were discussed. During those meals the child received attention contingent on his refusal to eat or other inappropriate behaviours, such as throwing his food on the floor. The parents were unable to ignore the behaviours they found unacceptable and to limit their attention to praising positive eating habits. A long term individualized treatment plan would be necessary to reverse this pattern of behaviour.

By the termination of the pilot study this little boy, who was now 24 months old, was helping to wash dishes, enjoyed having books read to him, and was independent in attempting to dress, particularly if it meant going outside to play. His behaviour with strangers showed appropriate distancing. He was gentle with his infant siblings except when he wanted to hug them and did not realize he could hurt them by hugging too hard.

Child #2. Child #2, age six months at intake, quickly gained weight from below the 3rd percentile to just below the 5th, levelling there for a time and then moving on to the chart just at the 5th percentile. Her height maintained a level between the 5th and 10th percentiles. Her intake improved when the mother began to feed her mashed food she had prepared for herself and her husband.

This child was able to take steps, could crawl well, had fine finger movements, and was starting to say words. She would not approach a stranger and became very upset when the researcher cared for her during her mother's doctor appointment.

Child #3. Child #3, age 20 months at intake, gained from below the 3rd percentile to between the 10th and 25th lines on the chart. His height remained well below the 5th and his head circumference at the 5th percentile. The fact that these remained unchanged meant that the weight gain would have to be sustained over a long period of time before catch up growth could be expected. This child's twin sibling experienced a greater velocity in weight gain from below the 5th to between the 25th and 50th percentiles during the study. His height remained on the 5th percentile while his head circumference was on the 25th. At the end of the study Child #3 was walking around furniture, but not independently, although he had passed two years of age. He remained solemn, rarely laughing, and with little speech. He continued to watch the world through large expressionless eyes.

Child #4. Child #4, age 35 months at intake, gained some weight but remained below the 5th percentile for both his weight and height. This occurred despite the fact that his caloric intake was greater than required for catch up weight gain. His head circumference remained between the 10th and 25th percentiles.

The day care workers and mother used a communication book to ensure that activities learned at day care were continued at home. Nine months after intake into the study he was making short sentences, could quickly put together puzzles, and was learning to play well with other children. He continued to be extremely active and very agile, climbing over and under everything he could.

Child #5. Child #5, age 14 months at intake, had gained some weight in hospital which she maintained on discharge. On all the anthropometric parameters she remained below the 5th percentile until six months after intake when she reached just above the 5th percentile. This child had several disruptions in her routine after discharge, when she and her mother moved three times in a six week period. Although her eating patterns had

regressed to where she again was controlling what she would decide to eat during that time she soon reverted to feeding herself and started to gain weight. She was walking well on her own, was developing her fine motor skills, enjoyed having books read to her, and was generally laughing and smiling. This little girl had the ability to make others smile when she smiled at them. In contrast to the initial contact, the mother and child attachment had increased dramatically and it was obvious that both now enjoyed the others company. The parents had separated and at termination of the study the mother and child were living in their own accommodations.

The Parents

Recognition of problem. Three of the five mothers/parents recognized that their home environment was influencing their children's ability to grow. One of the mothers was aware of the potential effect of the marital discord on the child while two others, once the subject was broached, were willing to acknowledge the possibilities. However, none of the parents were aware of the potential long-term negative consequences to the children if the failure to thrive were not rectified.

The impact the home situation was having on the child had been emphasized as part of the complex etiology of the FTT. These parents had few successes in their lives and placing an emphasis on the home to the exclusion of all other factors would have served little purpose. There was variable parental acceptance of the diagnostic and intervention recommendations.

One of the mothers was not able to acknowledge that psychosocial problems were affecting her children. This mother kept repeating that if everyone would just leave them alone everything would be fine. The fact that at 27 months of age two of the children were developmentally delayed did not effect any change in the mother's behaviour. By

accepting the mother's denial and decision that there was little to change, the child welfare workers helped maintain this status quo where the children continued to function at less than that of which they were capable.

For this family the child's admission to hospital had precipitated a crisis at which point there may have been an opportunity to effect some change. Once the child returned home, it became difficult to create an arena in which the mother would agree to accepting assistance to improve the physical and developmental status of the children. The older child in this family was not allowed outside to play nor did he have any playmates other than his brothers. The mother would not discuss day care as an opportunity for her children to learn to socialize with other children.

The fifth mother would not believe that there was not a physical basis for her child's slow growth. This mother stated that her child was "bad" because she did not eat, sleep, and grow as well as her friend's daughter. She would not listen when told by health professionals and a worker speaking her own language that the amount she was feeding her child was contributing to the growth failure. She became visibly upset when the child was fed more than what she had decided was sufficient. Gradually role modelling and teaching effected change, but some restrictions remained at the termination of contact.

Assistance. Two of the mothers, when problems arose, felt comfortable contacting either the social worker with whom one had contact and/or the researcher in the other case. They sought reassurance, as much as assistance, that all was proceeding as it should with their children. The assistance two other families received consisted of regular visits to the physician, visits from the public health nurse for one family, and visits from the researcher in both cases. The researcher then served a dual role of counselling the mother and collecting data for the study.

One mother received homemaker service two to three times a week, meal planning

and budget counselling, and infant stimulation services. Another mother received homemaker services which were attuned as much to stimulating and working with the child as to working with the parents. When a crisis prompted the mother to move out of their apartment, income security provided assistance to set up her own apartment. Day care service for the purpose of infant stimulation and socialization was obtained.

In one of the five families the child attended day care on a regular basis where he received attention from a special needs worker. The mother worked closely with this worker to maintain the momentum established at day care. Child Development Clinic and community services personnel were developing long term plans to assist this child into the school system and beyond. Occupational, speech, and physical therapy workers from a centre for handicapped children conducted an assessment of the child's functioning with no focus on possible causes of delay. The day care workers and the mother then participated in the care plan that was adopted to maximize the child's capabilities.

This mother had been referred to the Parent Support Program which provided a parent aide. The parent support worker assisted the mother to improve her life skills that would enable her to make other positive changes in her life. She told the researcher that weekly meetings were alternated to allow for pleasurable activities one week and work sessions the next. This mother was willing to accept any programs offered that would help her and her child improve their home situation.

The Professionals

Each family received intervention determined to be the most effective within the parameters of what was locally available within the social and health care fields. Members of the interdisciplinary team varied depending on: a) the service delivery required, b) the child's level of FTT and, c) the district in which the family lived. Families #1 and #2

received relatively few services from either hospital or community workers. The public health nurse had visited several times when child #1 was very young but had not been involved for over a year. This mother had attempted to obtain child care assistance in order to continue to work when she and her husband had separated. When this was not forthcoming she, after trial and error, had found someone to care for the child while she worked. When her sitter became pregnant and could no longer babysit this mother did not see any value in attempting to seek service from an agency and found a sitter within her geographic area. However, she did obtain homemaker service postnatally to allow her to visit the twins when they remained in hospital because of low birth weights.

The researcher served as a counsellor and listener with whom the mother #1 could discuss problems and search for solutions. The realities of attempting to keep appointments with other professionals, particularly after work, precluded seeking that assistance. The parents were aware the social worker was interested in helping them but the father refused to acknowledge that any part of the problem was his. Therefore, he would not meet with the social worker, telling the mother that the problems were hers alone. The dietitian assessed a three day intake of their child six months post discharge and suggested methods to increase his intake.

The dietitian was seen by all families to be non-threatening as she focused on foods eaten and on methods to improve intake, but not on the causes of the problem. This was acceptable to all parents involved in the study.

Besides the physician, the public health nurses were the health care professionals most involved with family #2. Over the span of the child's first year, three nurses had visited in the home to role model feeding and provide health care teaching. One nurse in particular, had taken the mother to a young parents centre, had taken knitting patterns to her, and had generally responded to the mother's needs beyond those expected of a public

health nurse. This mother expressed great pleasure and appreciation for this nurse's interest. Regular telephone communication between the public health nurse, the social worker from the immigrant women's centre, and the coordinator/researcher was important when arranging to prevent too many visitors one week and none at all the next. Consistency in teaching and in role modelling was thus maintained.

A cross section of the workers involved with the various families were interviewed to ascertain the strengths and weaknesses of programs from their perspective. Three families were in contact with multiple workers. Nine out of ten professionals identified close communication as imperative in the provision of care to assure that needed services were provided and that duplication did not occur.

Family #3 received the services of ten different disciplines: nursing, medicine, dietary, child life, infant stimulation, child welfare, income assistance, child protection, budget and nutrition, and child development workers. In team meetings the health care workers expressed opinions regarding the FTT and devised intervention strategies. However, because the mandate for child care remains with the child welfare workers, the suggestions and concerns were taken under advisement but were not necessarily implemented if the child welfare workers did not agree.

In particular, for two families there was a noted division into two separate "camps" with the health care workers suggesting more stringent actions than did the child welfare workers. One newly graduated child welfare worker was assigned to one of the multiproblem families. In speaking to the researcher, this worker stated that no matter what the health care professionals suggested, this worker was going to leave the children in their home. She said that she could not understand the anger of the health care workers. The researcher explained that the health care workers, some of whom had 20 to 30 years of experience, repeatedly saw the same children and became frustrated by the lack of change

in family functioning. The experience of all the long-term professionals in caring for children who were abused, and in some cases who had died because of their injuries, caused these persons to advocate actions they deemed necessary to prevent potential abuse. This worker's supervisor was invited to attend the team meetings to assist and support her to interpret material and to make decisions.

Because of ever changing workers within the system there was little consistency in the follow up of the families requiring child welfare support. When there were conflicting opinions about the method of intervention for two of the families, the parent(s) were able to create greater divisions to their own benefit. Families were considered non-compliant when they refused to participate in assessment and intervention strategies.

Health care professionals, in turn, had difficulty accepting that psychosocial causes alone could cause a child to stop growing. For child #3 the researcher was told by both nurses and physicians that "...there had to be something physically wrong with the child because his development is so delayed". When all the test results proved to be normal, and the child quickly gained weight the comments switched to "...that is a social problem. You can look after it". Nursing staff did not appear aware that, when parent(s) overheard comments such as "...you need to watch those parents", they perceived they were being judged as unfit, because their children were not thriving as a result of their detrimental actions and inactions.

Health care staff in the hospital expressed concern when children were discharged home before comprehensive therapeutic plans were developed. When they feared that one child might come to harm if signed out from hospital while the parents were separated and neither parent had been attending hospital regularly to learn child care, they contacted the child welfare agency. They then expressed great frustration and anger when there was no response from the agency for a week. When a hospital social worker stated that this length

of time was unacceptably long, the agency worker tried to explain the process the agency followed. Because this worker had previously spent 15 years or more in the community, she did not appreciate the explanation. This had the effect of increasing the hospital staff's frustration and annoyance with the lack of any progress to effectively intervene with the child.

In turn, hospital staff appeared to be unaware of the effect their behaviour had on families. One family member told the researcher of an incident where the family were in the playroom with the child when a nurse came into the room, picked up the child, and walked out without saying a word to the parents. This left the parents feeling as if the child did not belong to them any more, but to the nursing staff. They were distressed to overhear someone say the reason that their child ate in the playroom, when others were not allowed to do so, was because the staff had to watch the parents.

Parent(s) questioned the researcher about the causes of FTT. Questions about what they believed to be a factor in the development of the syndrome often provided insights into family functioning about which the family were aware but had difficulty articulating. Explanations that did not criticize their actions were effective in presenting the parent(s) with material which they could consider. Conversely, ordering parent(s) to perform certain actions or to refrain from others only produced anger and resentment.

Family #4 received the services of multiple agencies that provided a coordinated effective approach to intervention. This mother had accepted, before anyone told her, that her child was growing too slowly. She received service from income assistance, child life, medicine, nursing, day care, community services, child development, dietary, a parent support program, child protection, and a child welfare worker. In this family, the experience of dealing with the child welfare worker was positive because the mother engaged the worker herself. This mother sought help and telephoned the researcher to ask

about admission of the child for assessment.

The mother made efforts to enlist the help of a community group to assist her in learning skills that would prepare her to become employed. Regular meetings, in which the mother either participated or received full reports, were held with her knowledge. This then provided a cohesive group where all worked toward the same goals and objectives. These professionals were rewarded by watching the child progress developmentally while his mother found great pleasure in his achievements and in her involvement.

The researcher and personnel at The Child Protection Centre analyzed data collected during each step of the data collection process. This was necessary, not only from a research perspective, but to assist in generating the most effective individualized programs possible, within the constraints of the system. This resulted in the discussion, conclusions, and recommended program that is outlined in the following section.

PART III

DISCUSSION AND CONCLUSIONS

CHAPTER VII

DISCUSSION OF THE STUDY PROGRAM

Children

Weight gain. All the children enrolled in the pilot study gained a small but measurable amount of weight which was demonstrable on the growth charts. This weight gain for three of the children was the result of caloric intakes beyond that needed for maintenance of growth (see Table 3). The catch up growth for these children must be continued over a sustained length of time before it will be possible to detect increases in height and head circumference for two of the children.

Two of the children sustained current growth levels because their caloric intake was at maintenance levels only for their weights. One of these children was very active and therefore had a high metabolic rate while the other continued to refuse to eat large amounts. The graph of the percentile levels that were reached and maintained demonstrates the growth that occurred (Figure #3).

TABLE 3 - Growth profile

Children	1	2	3	4	5
Admission Weight	9.04 kg	4.575 kg	7.85 kg	11.7 kg	7.86 kg
End weight	10.6 kg	7.8 kg	11.2 kg	12.2 kg	9.4 kg
Total gain	1.56 kg	3.225 kg	3.350 kg	500 gram	1.54 kg
Daily gain	8.6 grams/day	12 grams/day	27 grams/day	4.4 grams/day	10.2 grams/day
Admission Percentile	< 5th	< 5th	< 5th	< 5th	< 5th
End Percentile	10th	< 5th	> 10th	< 5th	> 5th

Grams per day needed for maintenance of growth percentiles:

Birth - 5 months	20 - 30 grams
5 - 12 months	13 grams
More than 1 year	7 grams

Weight Patterns

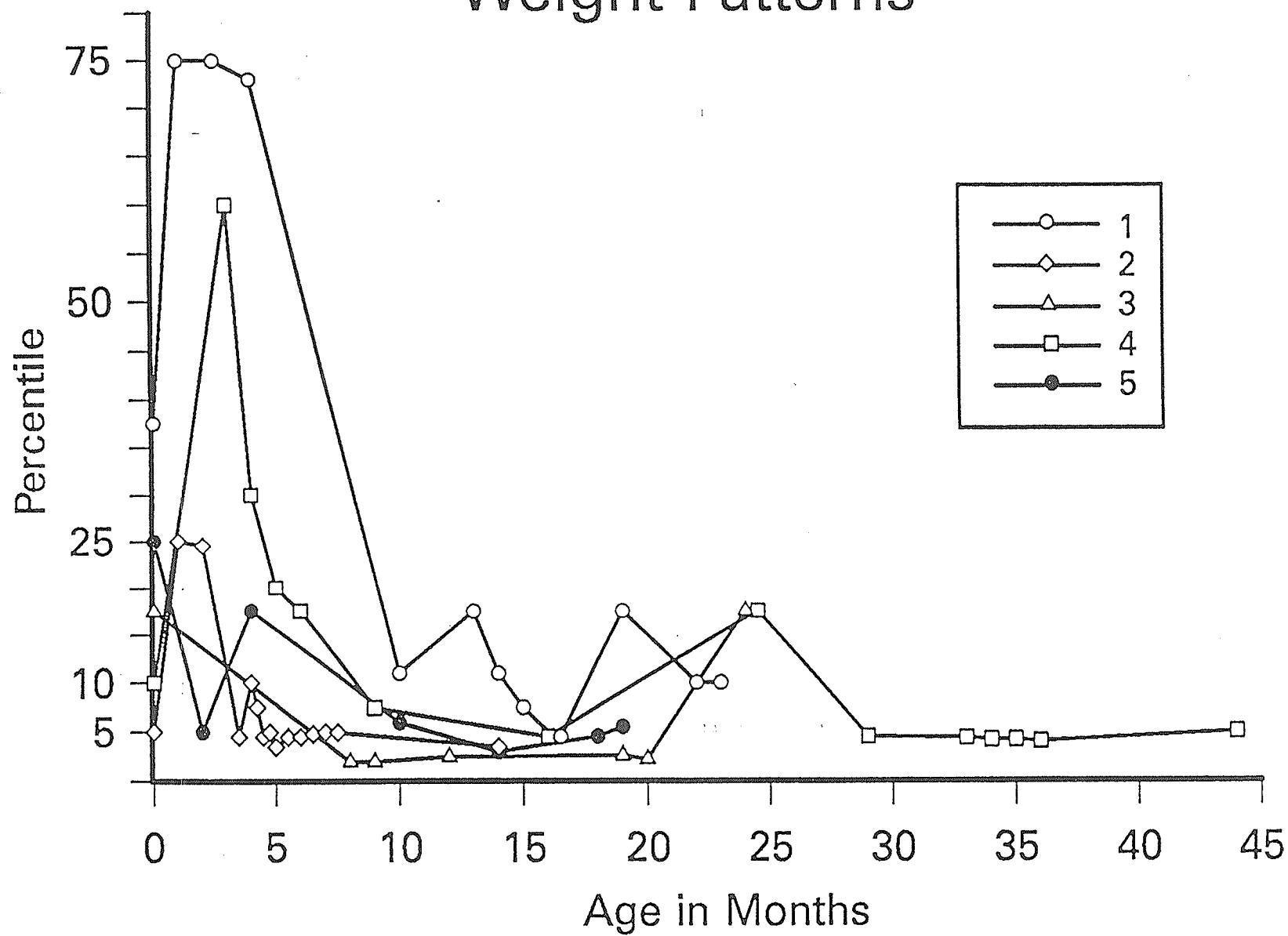


FIGURE 3 - Weight Gain Patterns

Developmental gains. One child did not require developmental testing as her pediatrician judged her developmental level to be appropriate for her age. Two of the children were tested as appropriate for age and did not require further testing. Two of the children tested as delayed with successes much below those expected for their ages.

Prior to his admission, one child who was twenty months old, was experiencing successes at an eight to ten month range. After one week of hospitalization he was successful at completing some tasks at the eighteen month expectancy. When he was retested at 24 months he had maintained these successes but remained four to five months delayed in most tasks.

On his initial assessment at 37 months of age the fifth child averaged successes at 27 months. He was able to complete some tasks at the 30 month level but other testing was at the 24 month level, thus averaging 27 months. After six months the child had additional successes but his overall performance maintained a delay of 10-12 months. The child when tested at 46 months, after another four months attending daycare daily, demonstrated greatly increased verbal and fine motor skills. The mother and all practitioners working with the family were encouraged by the gains the child had made.

It is possible that the attention focused on the children and their families while participating in the FTT study was responsible for the positive responses evidenced in the growth and development of the children. Comparison to an untreated control group would be needed before a more definitive statement could be made. An alternative means of assessing the benefits of the program would be to select a control group of five from all the children diagnosed as failing to thrive during the same time frame. The physical and developmental successes of those children could then be compared to the children who participated in the intervention program. These comparisons extend beyond that proposed in the current research project.

It was possible over a period of eight months to identify changes in the children's weight and developmental quotients. However, it must be remembered that a longer period of up to two years is required before any height and head circumference changes indicating

a more sustained development could be documented.

Issues Identified From Intake

Assessment

Referral to the Program

There was limited referral, with only 14 of 54 children admitted for FTT actually referred to the program. With the strict criteria for definition of the syndrome, children who were beginning to drop off their growth curves or who were maintaining low weight curves could not be accepted into the program. This meant that children who were in the early stages of difficulty were unable to be accepted into the program until more major problems occurred. The opportunity to intervene before more drastic changes occur in a child's growth profile is lost when referral is not made based on more broad criteria.

Etiology of FTT

The heterogeneity of the etiology of FTT meant that attempts to focus on one simple cause was not effective in the total intervention. Although it is possible to rule out specific organic causes of the FTT, organic elements to the problem cannot be excluded. Environmental factors are extremely varied and must be carefully identified before strategies can be devised to eliminate negative elements and complement positive ones.

In none of the cases was one single factor responsible for the children failing to thrive. Factors common to all of the cases that were consistent with research findings in other jurisdictions included;

1. The mothers were the main, and in 3 of the 5 families, the only caretakers of the children. These mothers were unable to identify consistent and constructive supports for themselves.
2. Marital strife was a component in all of the families. The single parent mothers had stormy relationships with their former husbands and/or boyfriends. Within the long term married and common-law relationships there were ongoing disputes and tension.

3. The mothers had difficulty when they attempted to discuss their childhoods. There was little that was happy or pleasant that they could remember when growing up.
4. Losses that the mothers had experienced through the years of friends, family, parenting skills unlearned, opportunities and stable homes added to their distress.
5. A lack of transportation served as a major isolating element for a number of families. Having to depend on bus transportation in the winter meant that most were limited in their travel.

Other potential influences for FTT, congruent with the literature were:

1. Some families did not have daily routines that provided structure or stability for the children.
2. Several children used food as a mechanism to control their environment. Parents stopped fighting when they were frightened by a child who refused to eat and began to lose weight to the point that admission to hospital was warranted.
3. The fathers who were in the family unit were not identified as caretakers of the children. One father would do nothing, so the mother stated, to assist with the child's needs.
4. Several mothers held the children at arms' length and did not cuddle or respond to the children's cues for eating or sleeping.

The professionals involved in the intervention must be knowledgeable of the multiple causations of FTT and willing to focus broadly on all possible factors. The tendency to prejudge and concentrate on one element rather than the amalgamation of a multitude of influences produced ineffective solutions, particularly when intervening with multiple problem families. The fact that psychosocial factors could produce such difficult and intransigent organic illness in children was not totally comprehended by all the professionals involved with the families. Another issue that was identified during the program was the lack of preparation of neophyte social workers to intercede with multiproblem families. This deficiency, coupled with a lack of supervision, of criteria for assessment and decision making, and of standards of practice, does precipitate situations where workers feel censured

by the other disciplines. Alternatively, nursing staff who became angry and argued with, and/or ordered families to comply with their instructions were ineffective in the intervention. In actuality, each person desired the best possible solutions for the children and their families but often prevented others from functioning effectively.

The health care professionals continued to search for organic causes for the FTT, particularly for one of the most affected children. In turn, the child welfare workers did not give credence to the devastating long term effects that can result if children do not receive adequate intervention at this stage. The professionals who concentrated on one child's developmental delay promoted the belief that the child did not have the capability to function at levels normal for his age. This concentration on the child's delays excluded familial factors that were contributing to the problem. This lack of a broad assessment of the total picture to plan therapeutic interventions for both the child and the parent(s) often produced an ineffective program.

Time Constraints

There was pressure on and/or from the physicians to discharge the children from hospital prior to a thorough assessment of the environmental situation of the child/family. Consults to the dietitian, to child development, and to social workers for assessment were often not completed before the children were discharged. This then produced a new set of obstacles, as arranging times for assessment were difficult to coordinate.

Many professionals find it a more effective use of their time if the clients attend sessions at their offices rather than the professionals commuting to the clients' homes. Families were often not able, or unwilling, to attend meetings at times suggested by the professionals, especially if the family members worked. Although the employer of one of the mothers was able to allow her to stay with the child while in hospital, this is not possible for all working parents. The mother noted that she could not abuse this privilege as she realized that her being away affected the workload of her colleagues.

The majority of professionals work a traditional 0900-1700 shift (except for nursing

that has a decreased staffing pattern during the off hours). This meant that any team meetings had to be scheduled to fit within those time frames, decreasing the opportunity for some of the families to attend meetings. Families of children who have organic problems, that do not carry the stigma that problems produced by psychosocial causes, are eager to seek diagnosis and treatment. Environmentally based problems place culpability on the parents/caretakers and, therefore, result in greater apathy in response to efforts to determine problems and plan interventions. It must be noted that these families are usually more dysfunctional and this attitude increases their low self esteem.

Planning

Language Differences

Within the disciplines involved with the child and family there are differences that have an impact on the design of intervention strategies. Language and terminology do not have the same meaning to everyone. In one case, the child welfare worker, speaking within the context of community caseloads, spoke of one family as "stable". This meant that the children were cared for physically, were not in danger of abuse, and some service delivery was being accepted by the mother. To the health care workers, the fact that services did not appear to be aimed to maximize the potential of the children made the situation unacceptable. Stable, but definitely unhealthy, was the diagnosis made by the latter group. Neither group of workers established that they were fully cognizant of the difficulties encountered within the alternate system in the attempt to communicate each point of view. The differences found within this program were clearly demonstrated by Hathaway (1989) in a statement that, if a child's physical symptoms and developmental status improve, the social worker has made a significant contribution. The researcher found that this attitude created problems for health care workers who expected that the maximum possible improvement was the only acceptable alternative to be considered. With each group working from a different set of expectations, it was essential to determine the most that could be realistically achieved given the home situation, the identified needs, and the resources

available that would or could be committed by those with the mandate to do so to the families. Educational programs that are presented conjointly for members of various disciplines would provide members with a common language and understanding. When attempting to establish intervention programs it is necessary to focus on the identified problems and on what resources are possible from each jurisdiction. All professionals must become aware of the different language and interpretations used by other disciplines when working in a multidisciplinary effort.

Priority setting

A conjoint issue was the focus of service delivery. The health care workers were concerned from the perspective of the children, while the child welfare workers clearly defined their focus as the mother and the children. These differing foci meant that in the community where the health care workers did not have jurisdiction, interventions had to be completely agreeable to the mother prior to implementing them for the children.

If the parent(s) did not see that a problem existed and refused to participate in the intervention, the dilemma created by these different objectives led to anger and frustration between the workers. Health care personnel function in an arena where their judgements are accepted by most parents with little dispute. In turn, the child welfare personnel are often viewed by families as the "opposition". This meant that, if the latter workers did not understand or believe that the condition warranted pressure on the family, or if the parent(s) refused to cooperate, the parent(s) could effectively stall the system. None of the parties were able to set priorities in those cases where these differences existed.

In contrast, for one child there was complete agreement on the priorities for service delivery. The child remained the focus of attention for all the professionals and for the mother. This mother was aware of the problems and sought help to rectify them. In turn, in conjunction with assistance for the child, the mother received education in child development. When the mother, working with an assessment worker, identified areas where she sought help for herself, services to meet those needs were added. A major difference

between these cases was the willingness of the mother to identify and admit that the child required assistance. An assessment worker was able to assist this mother to articulate the child's/family's problems and needs. Alternatively, one of the mothers agreed to participate but, effectively stalled any change within the home environment. She had articulated the problems with her children in a brief interview with this same assessment worker. Yet, when she worked with the community worker, she refused to acknowledge any problems and would not allow proposed interventions for her children. The first worker had many years of community service with multiproblem families.

A supervisor in the community identified that as cases were identified, if it was possible considering workloads, they were assigned to workers with expertise in that particular problem. Otherwise, relatively inexperienced workers would be assigned multiple problem cases. Supervisors assist with caseloads, however other priorities preclude meeting more than two to three times yearly. If actions included consideration of apprehension of children from their homes, legal issues and concerns affected the decisions made in the community. Precedence, the effect that a court judgement in favour of not forcing a family to comply with contract terms, and other legal ramifications have an impact on intervention decisions, in addition to the condition of the children. These issues are not considerations with which health care workers contend in the course of their daily practice.

Implementation

Health care workers functioned from the perspective that in a hospital setting everyone, including parents, agree to the best treatment possible for the child. This was not necessarily the case in the community. Although all the workers agreed that a specific course of action would be the best, if a mother did not agree, the workers with the legal mandate did not or were not able to enforce any action. This led to extreme frustration on the part of hospital personnel who voiced their anxieties for the children by saying "what was the point in reporting the case and planning an intervention program if the family do not have to follow through?".

On one occasion the nursing staff from a unit listed all the conditions for the child's discharge that either had been broken or had not been met. They met resistance when they expressed to the community worker their grave concern and attachment that had resulted from three months caring for the child. The statement from the outside worker, that they should remain detached and not become emotionally involved with the child, only served to create more anger and hostility.

The presence of the researcher was needed to remind health care staff about the program. If there were not daily visits to the unit children could be admitted and discharged before the researcher heard about them. Professionals continued to deny that FTT could be a result of psychosocial problems in which there was a potential for child abuse if the abuse was not already occurring.

Transfer

The province of Manitoba is divided into various agencies with the mandate for legal responsibility for the welfare of children. Within the city of Winnipeg itself are six child welfare agencies. Should families move from one jurisdiction to another they may be retained by the first agency for a period of time, usually no more than three to four months. After that time, the child is transferred to a worker in the new district. Even with extensive case notes, all the information garnered from the families cannot be exchanged.

This type of move led to a so-called reinvention of the wheel for one case while the newly assigned workers proceeded to relearn what was already known about the family. This was evidenced when a mother provided an elaborate scheme to pretend that she had not received her family tax credit. It was only at a meeting with several health care workers, and a chance remark that the mother was planning specific purchases with this money, that the community worker who had taken over the case learned the money had been spent months earlier. The lack of communication thus allowed the mother to invent explanations and activities that seemed plausible, unless one were aware of the history. Actions attempted a year before were repeated with little or no effect.

Because the major health care workers, the physicians, the head nurses, dietitians, and child life personnel did not usually experience this type of transfer, they retained the history of the child and family. In the hospital, if census allowed, children returned to the units in which they had been admitted previously.

The children who experienced the most positive gains were those whose parent(s) either did not move or moved only within their housing complexes. Although one of the mothers did not like her apartment, she renewed her lease because it was best for the child to remain close to his day care and to continuity of medical care. A sense of permanence was sought by these families and remaining within a familiar setting was one method to achieve this.

Service Delivery

Coordination

The researcher, within the action research framework, functioned as coordinator for these intervention programs. Several issues that emerged in relation to this arrangement were:

1. The researcher was employed by none of the agencies involved in the interventions. On several occasions it was noted by a variety of professionals that the program was a research project and therefore did not come within the confines of any one agency. Centering the program in one facility or agency would provide the authority and presence required.
2. The researcher was not well known to many of the professionals and credibility and knowledge about the syndrome of FTT needed to be established.
3. The need for coordination of the multiple services was clearly identified by all the professionals and the families. For some families there were multiple agencies that had limited contact with each other. Those who no longer were involved with the child and family welcomed information about the progress attained. The positive results served as a stimulus to act in an interdisciplinary team for future cases.

Community agencies rarely reported to the physicians and health care workers about the status of the children. The coordinator, by maintaining contact with all services, was able to inform each service of the activities of the others. This reporting was not as complete as was desired, as exemplified by one physician who noted he would have preferred more frequent information of how the family was functioning in the home.

4. The researcher/coordinator was not aware of the multiplicity of services available within the city and was constantly learning about new agencies that could provide various services for the families. It must be noted that different persons enlisted the services of different agencies. A coordinator would be able to compile and update lists of services to serve as a resource bank for children and families in need.
5. The researcher/coordinator was tentative in the two cases that included non-voluntary involvement of the child welfare agencies, serving only in the researcher role while the child welfare worker was responsible for service delivery and coordination. The researcher continued to update information about the status of the child, when possible, with other involved personnel and to seek information when it was not forthcoming.
6. The multiple community resources often involved with the child/family were not aware of the researcher, the condition of her involvement, and the credibility of the project. New services were added in isolation without contact with other professionals already working with the family. On several occasions it was in conversation with a community worker the researcher learned of the added input.

Professionals

Observations, interviews, and general conversation with both the parent(s) and the professionals provided the following insights:

1. Because frequently there are multiple disciplines involved with each family, detailed communication between and among these persons is necessary to prevent duplication

of services. Of great concern is the gap in delivery that occurs when everyone thinks that everyone else is providing the service. One person should be aware of exactly who is doing what with the child and family, and in which context. Duplication of service is costly to the health care system and frustrating to personnel who are repeating the efforts of others, as well as to the family members who must repeat their stories.

2. There should be one person consistently involved with the family to give continuity and stability. A public health nurse commented that, due to workload, emergencies, sickness, and vacation, in the period of eight months one mother had three different public health nurses. It would be impossible to prevent interruptions completely, but all should be aware of the confusion created in a mother visited by these different persons, all with varied emphasis and outlooks.
3. The professionals must understand the dynamics of the family and assess exactly what is happening, including the impact they are having on the family. In-depth psychosocial assessments and ongoing evaluations of each case are vital.
4. For all of the subjects studied, there were clinicians who demonstrated a lack of understanding that babies and very young children could and would react to the chaotic home life by refusing to eat. Education programs for professionals and for families are required to emphasize the effects of this syndrome on children.
5. As soon as a child began to gain weight there were recommendations to withdraw services because that was all that was perceived as needed. Professionals must be cautioned to refrain from telling parents that all is well just because the child is gaining. This is particularly true if the child's height and head circumference had been affected by chronic or severe malnutrition.
6. Social workers within the statutory agencies were not aware of the experience and knowledge of the health care workers, many of whom had twenty or more years working with children and their families. There were suggestions by these workers that health care professionals were not informed about the community system, nor

- about social problems. This added to tension and frustration between these groups.
7. Community social workers required education of the medical aspects of FTT. A supervisor acknowledged that because of high staff attrition, often inexperienced workers dealt with multiple problem families. Caseloads precluded close supervision by more experienced supervisors. This produced a less than ideal situation wherein the mandated workers, with the authority to compel compliance in the parent/family had little, if any, knowledge of the inveterate nature of the syndrome when environmental factors, that lead to the establishment and maintenance of the FTT, were not altered.
 8. A child welfare worker identified that social workers had difficulty treading a fine line to find the best solution for a child's problems. They had to ascertain that what might next happen to a child would not be worse than what they had already faced. Apprehensions to place children in foster homes are justified before a judge and are actions that are not taken without much assessment, thought, and planning. A major reality in the province is that foster homes are not always available. If at all possible, child welfare workers attempted to keep families intact. However, past research has determined that a temporary placement may be needed to stimulate a parent into action (Drotar, 1988).
 9. Nursing and hospital staff did not appear to be aware of the messages they gave parents. If a child suffered a physical illness, that was acceptable, and parents were given every possible aid. However, if a child failed to grow because of psychosocial problems in the home, a message, intended or not, might be "how could you do such a terrible thing to your child, you horrid people?" If parents are able to acknowledge that home conditions may be affecting the child, it is of little value to reinforce their feelings of low self esteem by emphasizing their role in the problem. One mother felt the implicit message given her by nursing staff was that they believed the child would or should be apprehended by the authorities and therefore the parents were not to be considered. The explicit messages on the ward did not

reflect this communication, however, the parents were not hearing what the staff thought they were imparting.

10. There existed a lack of knowledge of the capabilities, and a mistrust in the abilities and philosophical approaches, of other disciplines. As was noted previously, those disparate philosophies led to anger, frustration, and a sense of helplessness for some of the professionals as they contended with the realities of the situations. The professional family then began to act much as an abusive family wherein, the workers, feeling inadequate in coping with the problems of the family, acted as rival factions and conflicting opinions created splits in the team efforts.
11. Persons who participated on interdisciplinary teams for children with organic problems recounted the efforts of all members to build trust, consistency, and respect on the team before a cohesive group could be effective. It required time and an opportunity to assimilate the skills and the legal and professional responsibilities of each other. This integration into a unit is not possible if there are frequent changes in personnel and little or no commitment to the team.

Mother/Parents

The characteristics of the mother/caretaker/parents were consistent with those found in research studies conducted in other countries. The parent(s) were isolated, lacking friend and family supports, often in strife ridden relationships, and overwhelmed with their situations. Although two of the mothers were able to articulate the reasons for their problems, they lacked the self esteem that would allow them to seek viable solutions to their problems. Of note were the following considerations:

1. Although parents needed to be confronted with the fact their child was underweight and/or developmentally delayed because of their actions or inactions, criticism and condemnation produced few positive results. One nurse ordered a family not to change from the physician who had "reported" (referred) the case to the child welfare authorities. Once the physician's motivation in seeking assistance from the

authorities was explained to the parents, they reversed their intentions and continued to attend regular medical follow-up. Contending that parent(s) could not make decisions, rather than discussing problem areas with them and engaging them in effective change, led to confrontation instead of a partnership.

2. In one case, as soon as the mother noted dissension among the professionals, she was able to enlist the support of one against the other. The community social worker discussed with the mother an interview conducted by the assessment social worker and then gave permission for the mother to not attend any further interviews. The community worker did not communicate this decision to any of the other persons participating on the team. Three months later, the researcher, when evaluating the progress of this child and family with the community worker, was informed that this had occurred. Other involved personnel had been under the impression that the mother alone had made this decision. The mother had spent the past year circumventing the system and was experienced at noting the slightest hesitancy to maintain any previous agreements. She had gained the sympathy of the least experienced worker and continued to avoid confronting her problems. Thus a team decision was negated and no other professional had the power to effect any change.
3. Nursing staff were reluctant to provide parents with information that was not positive. There was an identified need to develop skills to give feedback to families in a positive, non-confrontational manner.
4. The mothers/parents' background of deprivation that resulted in them suffering from low self esteem provided obstacles in intervention programming. They had difficulty accepting assistance without feeling threatened by the professionals. Several were unable to understand the effect their actions and interactions were having on their children.

The program, as originally designed by the researcher, was effective to limited and varying extents in the assessment and intervention with the research children/families. The multiple variables involved in each case led to diverse programming and effects that included an eclectic mixture of personnel. No one factor could or would be isolated as causative nor as effective. Combinations of strategies, the personalities, experience, and education of all the persons involved, and, on occasion, timing all acted to produce the results obtained.

CHAPTER VIII

SYNTHESIS

The acceptance and use of the term failure to thrive (FTT), although the emphasis was on the child's inability to thrive, created feelings of inadequacy and served to further diminish already low self esteem in the parent(s). Slow growth did not evoke the same unhappy responses in the parent(s). The focus would then be on the slow physical growth of the child because of undetermined etiology. The ability to explain this slow growth in terms of malnutrition resulted in parents who were able to, or at least attempted to understand, the critical nature of the problem. The cause of the problem and the design of an intervention program tailored to the needs of the child/family centered on physical and developmental delays.

The data collected during the pilot study was summarized according to the investigator's original questions. Although the sample was limited to 5 of a possible 54 children the study children matched those in the literature from international studies. The sample findings in relation to characteristics, etiology, and issues of intervention are consistent with previous research. It is possible, had there been an intake of the entire population possible in the six month intake time, that the estimated percentages would have varied little from those found in the small sample.

Intervention Team

In two of the five cases where hospital and child welfare professionals worked with the families, the practitioners exhibited distinct feelings of concern, mistrust, competition, and even anger. They lacked a shared frame of reference regarding assessment and intervention with the families. The need for a common language was emphasized by the

misunderstandings that developed during discussions about management issues. A cohesive team effort was missing and therefore, the professionals had difficulty developing a consensual approach to the families.

Inexperienced workers, both in hospital and in the community, resisted the involvement of others and withdrew or acted in opposition to the judgements of other workers. A newly graduated social worker explained that the health care workers angered her when they made judgements without adequate information. In turn, this worker made intervention decisions that had an impact on other workers and that she neglected to share with the affected personnel.

Nursing staff exhibited frustration that was implicitly, if not explicitly, transmitted to families and other professionals. Close supervision of workers dealing with abusive and neglecting families was an identified need. The researcher questioned whether the desire for professional reassurance took precedence over the needs of the child and family.

Question #1 What are the interventions needed for children who are failing to thrive?

The specific actions required for intervention with children who are failing to thrive and with their families have been discussed in the context of each case study. Each child in the study required a different subset of actions to address the problems and needs identified for that situation.

Basic to all the cases, was the identified need for in-depth psychosocial assessment and for a forum where professionals pool and interpret their information. This would serve as a starting block in designing the treatment plan. The literature is replete with the premise that these in-depth assessments occur. Based on past experience and on knowledge gained

from this pilot study, this researcher has found that in-depth assessments are not as complete as required for effective intervention. The family that had the most extensive assessment continued to demonstrate gaps in information available. The assessments of the other families illustrated large segments that remained incomplete.

No family refused diagnostic testing for physical causes of the FTT. Psychosocial problems necessitated introspection and examination of the parent/child history and interaction. Most families find this exercise threatening and frightening while many professionals are not comfortable probing into the parent(s) backgrounds. Often there was a point at which, when the clients did not engage, the professionals withdrew and accepted their decisions. In the case of a child who is failing to thrive, workers must continue to seek engagement with the family because the child is at risk.

The development of a cohesive core of an interdisciplinary team that could then add or subtract disciplines as needed, would be an asset for treatment planning. Families must be included in the discussions regarding the problems and needs. This does not mean that professionals should not be able to meet without the parent(s) present to examine issues and obstacles that they may feel constrained from doing in the parents' presence. Parents must be kept apprised of the determinations and have input that is valued by the workers. Mutual frustrations and annoyance must be resolved before effective actions can occur.

Question #2 What are the benefits of instituting a nurse coordinated program for children with failure to thrive based on environmental reasons?

A nurse coordinated program would provide continuity and follow-up in environmentally based FTT. Nurses receive both health care and psychosocial instruction

during their education programs. They are educated to coordinate care delivery both in hospital and in the community, and because of their numbers, form a wide network of care deliverers. Communication with many interdisciplinary workers is a factor of every nurse's work life. By instituting a coordinated program the system would attempt to ensure that children suffering from FTT would not 'fall through the cracks'.

The coordination of the many different workers who may be involved with a family is needed to prevent duplication of service. Sheer numbers may overwhelm persons who are already having problems coping. Coordination would also help to prevent mothers/parents from playing one worker against another for their own ends. The benefit would come from one person who was aware of what was happening in the life of the child/family and who would communicate this to all other persons involved in the case.

Question #3 What are the constraints involved in developing such a program?

A major constraint in the institution of such a program is the fact that FTT programming has not been an identified need. Because the syndrome is not dramatically life threatening, a program was not seen to be a priority. There was also an assumption by health care personnel that the children were being referred to long-term resources when needed. A previous chart audit demonstrated that this was not occurring.

A number of the professionals interviewed identified that they were rarely aware of what transpired once a child was discharged from hospital; this included the physicians who, although they continued to see the children medically, were not up to date on what was occurring at home. The researcher identified a need to educate all professionals about the syndrome of FTT and its long term negative sequelae. Physicians and social workers must be able to evaluate the values of a nurse coordinated interdisciplinary team approach to

intervention before they will refer children to a program.

The process of working with the children and their families is time consuming and stressful. The coordinator must have the opportunity to visit the home to make an individual assessment of the conditions. This applies also to other areas such as day care centres, and to other agencies used by the team for intervention. This provides the coordinator with an understanding of environmental issues that is necessary when attempting to integrate the efforts of each professional. Phone calls, discussions with multiple workers, and family meetings consume a large portion of time. Long term follow-up that is suggested in other studies would require a commitment of up to two to three years for all children and their families.

The stress and frustration that a coordinator would experience working with multiple problem families and with many varying workers could be a source of burnout. The researcher was made aware of this potential problem by a noted professional in the field. He expressed the hope that the researcher would be well supported during this study, because of the anxiety and distress he had noted in himself and others when attempting to intervene with families of children who fail to thrive. The insidious nature of the problem adds to the difficulties experienced in developing intervention strategies. Internal struggles by some workers within the team, caught up in their own needs to prevail over other workers, could overshadow the need to adequately assess and plan interventions.

Question #4 **Would it be possible to measure benefits to the child who is failing to thrive and/or to the family over a limited period of time?**

As identified it was possible to measure physical and developmental changes in the

study children. The original time frames allotted in the study, of a three month follow-up, was exceeded by three to seven months when the families were followed from six to ten months. A two to three year follow-up would be necessary to assure that the changes were maintained. Family functioning was assessable in the longer time frame but would not have been possible in the three months originally proposed. There was a need to spend several months developing trust in the parent(s) who had not often experienced positive interactions with health care or child welfare professionals. It should be noted that if the parent(s) were able to develop one trusting relationship with just one professional, they then gradually extended this trust to others, being cautious during the process. In one case, the person who was most trusted by the mother was a support worker; in another case it was the assessment social worker. The level of trust appeared to be tempered by the parent's perception of the worker's acceptance of the family member(s).

Question #5 Would it be possible to determine what interventions initiated as part of a pilot study were effective and which were not?

Parents and professionals were interviewed to determine the strategies that were effective in the program as designed. The strategy identified by most professionals was that of communication between disciplines. Many noted that they often functioned in isolation from others, sometimes repeating what had been done earlier.

One worker suggested that a checklist of assessments that could be placed on the child's file would be a useful tool when determining what had yet to be completed. Actions that were determined to be unnecessary in a particular situation could be omitted. Team meetings would then be based on the findings from these investigations.

Families appreciated having one person who was their main contact person. As

noted before, this one consistent person was not always the coordinator, although in two situations the coordinator served as the one and, on occasion, the only person regularly visiting in the home.

Financial resources, and the ability and knowledge of where and how to access them, was another factor that assisted families. The opportunity for two of the children to attend day care to provide the child additional stimulation was made feasible by workers who knew how to gain access to the system.

Receiving positive feedback when the children began improving was important to the families. They needed to know that through their efforts the children were growing and developing. Conversely, parents who were not following through with behaviours needed to prevent long-term negative consequences for the children, had to be given that feedback.

Question #6 What type of program should be developed that would benefit FTT children and their families, including the various disciplines that may be necessary to promote family functioning?

It is possible to revise the original program to produce a potentially more effective procedure. Specific steps to be followed, in either an outpatient or inpatient setting, could provide a consistent outline, within which individual interventions would be planned. These will be presented in the recommended program that completes the concluding chapter.

It must be noted that several elements are necessary before any program could and would be useful:

1. The program must be recognized as official within the organization, and accepted by other agencies.
2. Physicians must be supportive and willing to have their patients involved in

a long-term program.

3. The entire program must be viewed as a positive process whereby all participants act to produce the best possible outcome for the child/family.
4. Educational programs enabling hospital and community personnel to understand the dynamics and treatment needs of parents and children who are failing to thrive is an essential phase in the introduction and ongoing program development. A clear delineation and understanding of the function and expectation of each professional role is vital. All roles, whether for long or short periods of time, are of equal value.
5. The coordinator must have credibility with other professionals, otherwise he/she will not gain the trust of both families and other professionals.
6. Skills and comfort in working with non-compliant clients are essential for people providing direct service to these families, as are acceptance and respect for the clients as individuals.

Limitations

Although there is agreement with findings in earlier research projects, this small sample limits the ability to generalize findings. The number of contacts with the families over an extended period of time does add credence to the observations. Because there was extensive contact amongst the researcher, the families and professionals, actions and attitudes displayed on one occasion were verified over the length of the study. The reliability of conclusions about the actions of professionals and family members could be determined by further observations under different circumstances.

The combined role of researcher and coordinator may have introduced a bias into the research findings. Parent(s)' responses to the researcher visiting in their home(s) may have been tempered by the fact that several of the mother(s) viewed the researcher as a positive support for themselves. It was difficult for the researcher to maintain a balance between focusing on the research objective and being involved in the intervention program.

Sample selection was not randomized and was dependent on the parent(s) agreeing to participate. The characteristics of the families who were not referred to the study, or who refused to participate, may have yielded a more intransigent sample. The match to the findings of previous studies suggests that this did not happen but a comparison amongst all the FTT children's charts would be required before a more definitive statement could be made.

Implications for Nursing Practice

The most dominant finding of the study is that nurses must be ever cognizant of their attitudes toward their patients/clients and their families. Although nursing curricula are replete with teachings regarding acceptance and tolerance, when caring for patients/clients, it was noted that anger, frustration, and fear for the children overshadowed these

convictions. This is not to say that nurses must accept all actions of the family members. However, as professionals they must be able to accept the person behind the action before a therapeutic relationship can develop. Nurses must also be able to recognize the affect their actions, intentional and not intentional, have on the patients and their families. Body language and non-verbal communication had a powerful impact, especially when they family perceived those actions as a condemnation of the family members.

Nurses were the professionals who least attended the information sessions about the study. Although other disciplines are able to set aside blocks of time to allow all to attend sessions, nurses had to provide constant coverage for the patient/clients. If a unit became busy, the nurses were unable to attend. If the professionals with the most intensive contact with patients are to remain apprised of current information, alternative methods of inservicing nurses about new programs must be sought.

The pilot study of the coordinated program for intervention with children who are FTT has examined the effectiveness of actions and inactions for a limited sample of patients/clients. The need to collaborate with multiple disciplines was emphasized because no one discipline is able to support a family through the many steps required to resolve problems that cause and exacerbate the child's FTT. The necessity of understanding the limitations, philosophies, and systems under which these other disciplines function cannot be over-emphasized.

The psychosocial basis to the syndrome highlights how essential for nurses is an understanding of the dynamics of attachment and interaction. The ability to observe and interpret interactions between the parent(s)/child(ren) must be prerequisite to determining interventions.

Nurses identified that they rarely received information about children for whom they had cared once the children were discharged. Feedback, in particular if it were positive, had

the effect of reinforcing interactions and efforts with the next families. If workers knew that they had been effective in helping a child/family to institute change, they were more amenable to attempting those actions in the future. Positive feedback from nursing staff to families was noted as producing and maintaining favourable change.

Implications for Nursing Research

One question the researcher received throughout the study was "why are you studying that type of problem? That is for social workers". The fact that nurses encounter social problems throughout their practice, in multiple settings, did not appear to be recognized by many other disciplines. The frustrations felt by many nurses when confronting these issues demonstrated that research from the perspective of the practising nurse is essential to help resolve concerns that affect practice.

The descriptive pilot study examined a practical problem, introduced change, and evaluated the actions used to introduce the change. The knowledge, generated in the context of social interactions, was based directly on that which was authentic and usable in the everyday lives of children, their families, and the professionals who must intervene to facilitate necessary changes to optimize child/family functioning.

To further assess the extent of the problem of FTT, as gauged by admissions to the referring paediatric hospital in the province of Manitoba, additional research projects are required. A review of the admissions for FTT for the past five years is needed to determine the numbers of children with the syndrome and the discharge plans as outlined on the charts. The next proposed step in the research program is the introduction of a long-term study of a designated program at the facility, with the opportunity to expand to rural and northern locations in the province. This would be an ambitious but worthwhile goal from the researcher's perspective. The positive results obtained within the small sample

inferred that, the potential to effectively intervene with FTT children and their families, could be significant in decreasing long-term psychosocial problems. As a result, society would benefit from the positive impact on these children and their families.

CHAPTER IX

RECOMMENDED PROGRAM

The objective of the pilot study was to investigate the implementation of a nurse coordinated multidisciplinary intervention program for children who were failing to thrive.

Factors considered in determining the effectiveness of the program were:

- 1) Families involved in the study had many and varied problems.
- 2) There were numerous professionals working with the families which was a costly process in terms of salary and time.
- 3) There were a variety of tasks that were required to constructively assist the children and their families.
- 4) Frequent communication was essential amongst the professionals.
- 5) The multiple systems required to address the issues were confusing and complex for the families.

Therefore the families, professionals, and researcher concluded that a coordinated program would be productive because:

- 1) The coordinator would serve as a pivotal point from whom workers could receive and to whom they could supply information.
- 2) There would be a more efficient use of time and resources if efforts were coordinated and not duplicated, or missed, thereby serving families more effectually.
- 3) A coordinated program would be cost effective in organizing and serving as a clearing house for information about the various agencies and programs available in the city and province.

The educational background of nurses include both health care and psychosocial preparation which equips them to act as coordinators of patient care. Communication and intervention with a variety of disciplines on a daily basis provides grounding to act in the coordinator role. The person working in the capacity of coordinator would require credibility amongst other professionals, experience, and concern for multiproblem families.

It is not possible to solely credit the coordinated pilot study follow up program with effecting the changes in the children and their families. Because there were many variables and situations for each case study, no one factor can be promoted as the basis for the changes in the children. However, the coordinated program was the common component amongst the cases. It may be inferred that there was an influence from the input of various disciplines but no other conclusions would be justified. The fact that there were positive changes in the children's growth and development may lead to inferences that there was an impact that would require substantiation by future research.

Although there is a wealth of literature on the subject of FTT, there has been little research into long-term intervention results. Because the negative sequelae that result from FTT are costly in terms of lost potential for the children affected and therefore, for society, long-term intervention program effects must be studied. It may then be possible to determine which preventive measures would produce healthy, energetic members of society.

Few professionals in any discipline understood the depth of pathology related to children who fail to thrive, nor did they have an appreciation of the length of time required for assessment and effective therapeutic intervention. Professionals working with multiproblem families require a knowledge base that includes: a) human growth and development; b) an understanding of the capabilities, legal constraints, and responsibilities of all members of the multidisciplinary team; and c) confidence that territoriality will not take precedence over the needs of the child and family. All inexperienced workers require

close supervision, education, and nurturing by their supervisors to prevent feeling that they are undervalued, misunderstood, and unsupported. The professionals must have an understanding of, an enthusiasm for, and well honed skills to work with non-compliant families.

The ultimate interests of the child and family must form the paramount catalyst for assessment and intervention with children who are failing to thrive. This does not preclude the decision that, on occasion, temporary or permanent removal of a child and/or the siblings may be required to prompt a parent(s) to act. In a multidisciplinary team framework the conclusions and information from all workers must be considered of equal value. Individuals who act in isolation on decisions that affect other team members or the results of joint planning may render the entire effort useless. Members of all disciplines must be committed to the concept of joint program planning and endeavours and must respect the rights and opinions of the other professionals.

In-depth psychosocial assessments based on comprehensive interviews with the parent(s), on observations, and on interactions of professionals and families are prerequisite before interventions may be determined. A cursory overview to ascertain the background and associations within the child/family unit is not a sufficient base for long-term programming. This component was most often incomplete throughout the pilot study.

A program that could be instituted for long-term research into effectiveness in working with children who are failing to thrive and with their families has been developed. A program to educate hospital staff and workers from external agencies about FTT and the benefits and requirements of a program must be instituted prior to the intake of any patients. The official sanction of both the institution and of medical staff would be required before there would be referral of patients to the program or a specialized clinic. It would be valuable to name such a program as a **SLOW GROWTH PROGRAM** in light of the

negative connotations that parents attributed to the term failure to thrive. This would also allow for the inclusion of children who do not meet the strict criteria of FTT, but who are beginning to show evidence of growth problems. Preventive programming could have a positive effect on the children and on their family functioning.

RECOMMENDED PROGRAM FOR CHILDREN WHO ARE SLOW GROWERS

Although **FAILURE TO THRIVE** is the recognized diagnostic title for the condition and would be used in explanations to parent(s)/family(ies) the term **SLOW GROWTH** would provide a less negative connotation and therefore will be used for headings and clinic name. Parent(s) must receive information about the syndrome and explanations about why the different terminology is used. This program must be recognized by and have the support of the administration and medical staff within the institution in which it is housed. This is required to maximize the numbers of children who are referred to the program. The assistance of the Medical Director of the facility is necessary to obtain the cooperation of the medical staff.

The Objectives of the Program:

1. To aid in the identification of children who are failing to thrive.
2. To assess child and parent/family functioning.
3. To develop a management strategy designed to assist the child/parent/family.
4. To provide coordinated hospital and community resources for continuing care.
5. To provide follow up to evaluate the effectiveness of the individual plan of care and introduce changes as needed.

Setting

The Program should be designated as a therapeutic program under the auspices of the Child Protection Centre at the Children's Hospital. The program should utilize both inpatient and outpatient resources at the hospital, dependent on the severity of the child's failure to thrive. Admission may be required for more severely affected children and for those unable to attend the outpatient department on a daily basis. Resources should be available to allow

nursing staff to observe parent/child interaction over meal times and during play over a period of one to two weeks. Recognizing that the hospital is an artificial milieu, interactions in the home must be added to provide a comprehensive picture.

Multidisciplinary Team

A nucleus of experienced members from several disciplines should form the basis of the multidisciplinary team. It is necessary that members of the core team be experienced persons in dealing with multiproblem families. The team would vary in size dependent on the requirements of the case in question. Individual assessments would determine the expertise that was required beyond that of the central workers who provide the following services:

COORDINATOR

- Receive referral of child
- Discuss with physician whether consults to assessment services have been initiated
- Case conference participant
- Liaise with external resources in conjunction with hospital staff
- Follow up with families at home
- Evaluate the individual programs with involved professionals
- Distribute follow up information

Based on the amount of time spent during the study a half time position would be sufficient initially, until the client load was built up.

NURSING

- Assess nursing care needs
- Plan daily care
- Document food intake
- Assess parent/child interaction
- Teach parent(s)/role model
- Case conference participant
- Receive follow up information

Ward staff for in-hospital admissions

SOCIAL WORK

Psychosocial assessment
Treatment recommendations
Case conference participant
Receive follow up information

One half time position as client load builds

FAMILY PHYSICIAN/PAEDIATRICIAN

Diagnosis
Medical treatment
Case conference participant
Follow up medical care

CONSULTANT PAEDIATRICIAN TO THE PROGRAM

Serve as a resource to team members and others regarding failure to thrive

CHILD DEVELOPMENT CLINIC

Assess child's developmental status
Case conference participant
Follow up assessment
Receive follow up information

Consultation and diagnosis

DIETITIAN

Assess child's caloric needs and intake
Recommend diet
Education of the parent(s) regarding child's dietary needs
Case conference participant
Receive follow up information

Consultation for both inpatients and outpatients

CHILD LIFE

Assess child's play/emotional needs

Role model for parent(s)

Assess parent/child interaction

Case conference participant

Receive follow up information

Staff on the units for inpatients and needs for clinic would require determination according to the evaluated need

SECRETARIAL RESOURCE

One third time person initially

PROCEDURE

Identification

- 1) All children who are identified as failing to thrive would be referred to the **Slow Growth Program**. The physician diagnoses the basis of the child's failure to thrive. Laboratory and diagnostic testing is completed.
- 2) Concurrently an explanation of the program is presented to the mother/family by either the physician or coordinator.
- 3) Children who are failing to thrive with an organic basis already served by a special needs program would not participate in the FTT program.

Assessment

- 1) Nursing staff on the unit or the outpatient clinic document precisely the child's daily food intake based on a dietary history as presented by the parent(s) and on observation. The dietitian will determine the adequacy of the caloric intake.
- 2) The nursing staff assess and document the child/parent interactions.
- 3) The nursing staff assess the child's routines of daily living -- feeding, play, cuddling, sleep -- and document on the nursing record.
- 4) The physician continues assessment of the medical status of the child.
- 5) The following consultative assessments are initiated:

Child Development for developmental assessment,

Dietitian to determine the caloric intake to promote and sustain growth,

Child Life to assess play/emotional needs and functioning,

Social Work assess psychosocial/family functioning.

Management Planning

- 1) All disciplines meet with the parent/family unit to design a plan of care.

Continuing Care

- 1) Nursing staff provide teaching of the parent/caretaker.
- 2) The coordinator consults external resources as determined necessary at the case conference to provide care in the community.
- 3) Ongoing communication with all professionals is facilitated by regular reporting to the coordinator who will compile and distribute the information to all involved professionals.

Follow-up

- 1) Ongoing assessment of the FTT child/parent/family unit may suggest changes in the plan of care as new needs are identified.
- 2) The coordinator will maintain contact with both parent/family units and professionals to evaluate the strengths and inadequacies in the program for involvement in restructuring the intervention program.

Discharge criteria

If the child is admitted to hospital all of the following should be complete before discharge:

- a) Child is beginning to show weight gain.
- b) Child is responding to social stimuli.
- c) All assessments have been completed or appointments arranged for same.
- d) Case conference to discuss assessments and plan interventions has been held.
- e) Coordinated services in place to assist the family may include:

public health nursing
child and family services
income security
teaching home-maker program
parent support program
day care, and others as necessary.

- f) Mechanism to update all services on the progress of the child/family that is understood by all parties.

Recommended Long Term Follow-up

- a) Medical follow-up with primary physician or children's clinic or clinic in community where child lives weekly x 2 weeks, if progress is satisfactory then monthly.
- b) Public health nurse follow up weekly x 2 weeks, if progress is satisfactory then monthly.
- c) Coordinator visits the home at 2 weeks and as necessary to assess and evaluate the program.
- d) Child development reassessment at 3 months x 1 year then as needed.
- e) Psychiatric/psychosocial/support services appointments as decided at the case conference.
- f) The coordinator receives progress reports every 3 months from all involved services, and compiles and distributes them to team members.

**** Research has shown that long term follow-up and service delivery of a minimum of two years is recommended because there is often a return to prior treatment status if care is discontinued before that length of time.

Conclusion

By enrolling children in this program for a period of two to three years following diagnosis of FTT it could be expected that there would be a positive effect on the growth and development of the children and on the family functioning. By coordinating resources determined necessary by an in-depth assessment of each case, effective management that includes family input would be instituted. Community follow up based on those identified needs would be communicated to health care personnel to consolidate the collaborative effort. Effective interventions would, in turn, promote the program and prompt further referrals of children who are failing to thrive. Once professionals have been involved in successful interdisciplinary efforts they are able to conceptualize the benefits of collaboration in other areas of their practice.

The long term benefits to the children would accrue from changing their nutritional state to promote growth and development. Well nourished children are more able to reach their potential. The ability of families to adapt and function despite multiple stresses could be influenced by the introduction of judicious supports and resources. Society would profit from a reduction in health care costs if the children do not require readmission for the syndrome. The ultimate benefit to society would arise from children and families that function at a greater potential than they might have done if there had been no intervention to assist them.

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APPENDIX A

Winnipeg, Manitoba
R (204

March 29, 1989

Dr. Heather Dean
Pediatric Research Coordinating Committee
Children's Hospital
800 Sherbrook Street
Winnipeg, Manitoba
R3A 1M4

Dear Dr. Dean:

I am a Master's student enrolled in the School of Nursing at the University of Manitoba. To complete the requirements of the degree, I am undertaking a study of children who fail to thrive. My thesis advisor is Dr. Erna Schilder, 474-9664. My proposal has received approval of the Ethical Review Committee, School of Nursing, University of Manitoba. The research project is a pilot study of an intervention program with children who fail to thrive that has been developed in conjunction with the personnel at the Child Protection Center. The intervention program will coordinate the efforts of the multidisciplinary professionals who practice both at the Children's Hospital and in the community. The Child Protection Center and the Child Development Clinic personnel have supported the creation of this multidisciplinary project. This project will study the implementation of a nurse coordinated long-term program to avoid duplication of services or, worse yet, the lack of needed care delivery.

I am requesting your approval to approach the physicians and nursing staff to explain the program and to obtain access to the children who are diagnosed as failing to thrive. The mothers/guardians of the children will receive a written explanation inviting their participation in the study. Should they agree to become a part of the study a consent will be signed. Potential benefits that may accrue to the family unit are a more unified service delivery program with all professionals informed regularly of the status of the child/family functioning and needs.

Ethical issues that are of concern are confidentiality within the parameters of service delivery, consent, and the right to withdraw from the program as described in the Explanation of the Study. Participation in the study will be for three months although it is anticipated that service delivery will continue for a minimum of two years.

In the present climate of cost restraint the costs and effectiveness of such programming is most relevant. A concurrent cost analysis of the coordinator's time and the noted benefits and impact of the intervention will be conducted. I am currently receiving a Manitoba Health Research Council studentship to assist in this program development.

Please contact me at home () or at the Child Protection Center (2811) should you wish to discuss this further. I anticipate hearing from you at your earliest possible convenience.

Sincerely,

Elizabeth (Betty) Thomlinson
R.N., B.N., M.N. Candidate

HEALTH SCIENCES CENTRE

DATE: MAY 25, 1989

FROM: Dr. D. Harper, Director of Research, H.S.C.

TO: MS. E. THOMLINSON

SUBJECT: Research Protocol Approval

NO: PEDIATRIC

TITLE: PROPOSAL TO STUDY THE IMPLEMENTATION OF A COORDINATED
PROGRAM TO GUIDE CASE FINDING AND INTERVENTION WITH
CHILDREN WHO FAIL TO THRIVE.

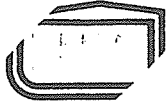
The above study has been reviewed by the appropriate H.S.C. Research Committee and has been approved.

COMMENTS: _____

Dr. D. Harper, Director of Research

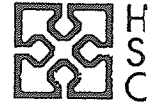
May 25, 1989
Date:

c.c. Mr. I. Shwartz
Revised: 13/4/87



THE UNIVERSITY OF MANITOBA

DEPARTMENT OF PEDIATRICS
AND CHILD HEALTH



133

Children's Hos
840 Sherbrook Street
Winnipeg, Manitoba
Canada R3A 1S1

(204) 787-

May 16, 1989

Ms. E. Thomlinson

Winnipeg, Manitoba
R

Dear Ms. Thomlinson:

The Pediatric Research Coordinating Committee has met recently, and, as I anticipated, there were no major concerns regarding your protocol entitled "Proposal to study the implementation of a coordinated program to guide case finding and intervention with children who fail to thrive", raised by Committee members. Therefore, the Committee has given your protocol full approval.

Sincerely,

H. Dean, M.D., FRCP(C)
Chairperson
Pediatric Research Coordinating
Committee

HD/ss

cc: D. Harper
C. Anderson

APPENDIX B

Explanation of the Study for Professionals

A coordinated multidisciplinary intervention program has been developed to care for children who are failing to thrive for any of the many reasons that cause this syndrome. Past research has shown that long-term care of a minimum of two years is effective in helping the children/mothers/families cope with this problem. Within the Children's Hospital and in the community a multitude of programs exist to assist families in need. To prevent a duplication of these services, or a gap in service delivery, the use of a coordinated program may prove to be most effective. It has been noted that knowledge of the effects and current status of the child would enhance the efforts of each professional's contribution to care delivery. The coordinator would communicate this information to update the files of the professionals involved.

An explanation of the program will be given to the legal guardians of the failure to thrive (FTT) child prior to participation, and a signed consent obtained. As failure to thrive often conveys to parents that they have "done something wrong" the term slow grower will be used in the explanation to the parents and on the consent form. Confidentiality of medical and professional involvement will be maintained as for all health care. Anonymity will be assured for the writing of the results and any potential publication of those results. Coding will be used for compiling the data for this study and the information kept under lock and key. The child/family maintains the right to withdraw at any time with no effect to the care of the child.

It must be noted that at any time should child abuse be suspected the legal responsibilities of the professionals involved, as defined in the Child and Family Services Act, Manitoba (March, 1986) would be followed as presently. This may not preclude involvement in the program as is determined at the case conference by the care delivery workers.

On completion of the study families and professionals will be approached to outline benefits, impact, and problems with the developed program. This information will then be used to revise the program for full scale implementation.

Program Guidelines Failure to Thrive

Children who fail to thrive comprise 10-20% of patients treated in ambulatory facilities and 1-5% of admissions to pediatric referral hospitals (Drotar, 1988). Failure to thrive (FTT) is a medical condition which results from biological and environmental factors. Long term negative sequelae that result when effective intervention has not been initiated include antisocial behaviour, growth deprivation, and decreased language and verbal skills which affect educational opportunities (Oates, 1986). The effort to assist the FTT children and their families requires the coordination of multiple disciplines to achieve the best results possible.

Failure to thrive is defined as:

- 1) weight consistently below the 3rd percentile for age, for children whose birthweight was at least 1500 grams and weight appropriate for gestational age.
- 2) weight for height below the 5th percentile curve; and/or
- 3) the failure to maintain a previously established pattern of growth.

This research project will provide a coordinated program for all FTT infants and children admitted to Winnipeg Children's Hospital. This project will assess the introduction of this program to provide guidelines for case finding and intervention. For the purpose of this study the researcher will coordinate these resources through the Child Protection Centre, Winnipeg Children's Hospital.

The Objectives of the Program:

- 1) To aid in the identification of children who are failing to thrive.
- 2) To assess child and parent/family functioning.
- 3) To develop a management strategy designed to assist the child/parent/family.
- 4) To provide coordinated hospital and community resources for continuing care.
- 5) Follow up to evaluate the effectiveness of the individual plan of care and introduce changes as needed.

Parents/families will be given an explanation of the program and consent obtained before intervention begins.

I) Identification

The physician diagnoses the child as failing to thrive because of organically and/or environmentally based reasons. Laboratory and diagnostic testing is completed.

- 2) Concurrently an explanation of the program will be presented to the mother/family by either the physician or nursing staff to invite discussion with the researcher/case coordinator.
- 3) Referral of the FTT child to the program once the mother/parents have agreed to participate.

II) Assessment

- 1) Nursing staff on the unit document precisely the child's daily food intake. The dietitian will determine the adequacy of the caloric intake.
- 2) The nursing staff assess and document the child/parent interactions.
- 3) The nursing staff assess the child's routines of daily living -- feeding, play, cuddling, sleep -- and document on the nursing record.
- 4) The physician continues assessment of the medical status of the child.
- 5) The researcher/case coordinator initiates the following consultative assessments:
Child Development for developmental assessment,
Dietician to determine the caloric intake to promote and sustain growth,
Child Life to assess play/emotional needs and functioning,
Child Protection Social Workers to assess psychosocial/family functioning.

III) Management Planning

- 1) All disciplines meet with the parent/family unit to design a plan of care.

IV) Continuing Care

- 1) Nursing staff provide teaching of the parent/caretaker.
- 2) The researcher/case coordinator consults external resources as determined necessary at the case conference to provide care in the community.
- 3) Ongoing communication with all professionals is facilitated by regular reporting to the case coordinator who will compile and distribute the information to the involved professionals.

V) Follow up

- 1) Ongoing assessment of the FTT child/parent/family unit may suggest changes in the plan of care as new needs are identified.
- 2) The researcher/case coordinator will interview both parent/family units and professionals to evaluate the strengths and inadequacies in the program for involvement in restructuring the intervention program.

Discharge criteria

All of the following should be complete before discharge:

- a) Child is beginning to show weight gain.
- b) Child is responding to social stimuli.
- c) All assessments complete.
- d) Case conference to discuss assessments and plan interventions has been held.
- e) Coordinated services in place to assist the family may include:
 - public health nursing
 - child and family services
 - income security
 - parent aide program
 - day care, and others as necessary.
- f) Mechanism to update all services on the progress of the child/family.

Recommended Long Term Follow up

- a) Medical followup with primary physician or children's clinic or clinic in community where child lives weekly x 2 weeks, if progress is satisfactory then monthly.
- b) Public health nurse followup weekly x 2 weeks, if progress is satisfactory then monthly.
- c) Coordinator home visits as part of research project at 2 weeks and monthly to three months to assess and evaluate the program.
- d) Child development reassessment at 3 months x 1 year then as needed.
- e) Psychiatric/psychosocial/support services appointments as decided at the case conference.

- f) The case coordinator receives progress reports every 3 months from all involved services, and compiles and distributes them to team members.

**** Research has shown that long term follow up and service delivery of a minimum of two years is recommended because there is often a return to prior treatment status if care is discontinued before that length of time.

APPENDIX C

Description of the Study

Dear Parent(s):

You are being asked to take part in a study of children who are growing slowly. This will help us plan the best way to use all of the services, here at the hospital and out in the community, to help you and your child. Elizabeth (Betty) Thomlinson will be doing the study. Her advisor is Dr. Erna Schilder, School of Nursing, University of Manitoba (474-8202).

A program has been planned that will put together all of the many kinds of services that are here in the hospital for children and their families. Once your doctor has decided what is needed by your child to help her/him grow, you will be asked to help in planning how that can best be done. Regular checkups with your doctor, just like you would always have, will be a part of this program. The nurses on the ward will take daily weights and check your child's height. They will show you on a growth graph where your child is compared to other children, and then throughout the program you will be able to follow your child's growth on that chart. The dietician will help plan what types of food would help your child grow the best.

The Child Development Clinic, after observing your child in your presence, will plan play and activity to encourage your child's growth. Other people will be asked to provide services to you at the hospital and in your home as decided with you, the doctor, and the nurses.

Betty Thomlinson will visit you at home two weeks after discharge, and then each month for three months to discuss with you what would be helpful to change in the program and what would make it better for other children. Your input into deciding what helped and what did not is necessary before the program can be made better for the next family. These visits would be by appointment and would take about an hour of your time for a total of three to four hours over the 3 month period of the study.

If you would like to hear more about this please sign below and give this to the nurse who will call Betty Thomlinson to visit to explain anything you would like to know. If you decide that you do not want to take part the care of your child will not be affected.

If you take part in this study the information will remain strictly confidential. Betty Thomlinson is looking forward to meeting with you to talk about this program.
Yours truly,

Elizabeth (Betty) Thomlinson

Yes, I would be interested in talking to you about what would be involved if I take part in this study.

NAME _____ Ward _____

APPENDIX D

Invitation to Participate

Hello. My name is Elizabeth Thomlinson. As you know from the form that you were given to read by your nurse or doctor I would like to study ways to help children who are slow growers. This is part of completing my degree in the Master in Nursing at the University of Manitoba.

I have been a head nurse on a children's ward in a rural hospital for the past 15 years. In this work I have seen a number of children who are slow growers and this is how I became interested in seeing if there are things that can be done to help. Some of the specialists in this area and I have drawn up a program to use all of the different services that are available in the best way possible. We need your help to decide which services are to be used for different reasons. At the end of three months we also need your help to figure out what helped, what did not help, and what could be done better.

Can I answer any questions that you have about the program? (Answers as necessary)

I expect you and your child will benefit from the program by having the services coordinated. The greatest benefit will be to future children who are slow growers because the program will be changed to use what we learn together is the best way to do things.

Once we have the program ready to use for other children it is possible that it can be written up to be published in a magazine for nurses and doctors to use in other places. If I write the results of what we learn I will not include anything that gives names or descriptions so that other people can guess about whom I am writing. The information of how to provide care is what I am wanting to let others know about. The suggestions I receive from you about your child and how the program is working will be kept under lock and key in my file. It will be used by the health care workers to provide service to you, or to change the program as decided by you and the team.

Should you agree to participate you will be asked to sign a consent to be part of the study. You may withdraw at any time if you wish without any consequences to the care of your child.

Do you have any other questions about the study?

Thank you for giving me the time to explain about this program.

APPENDIX E

CONSENT FORM

This certifies that I, _____
 as parent/legal guardian of _____
 agree to take part in the study conducted by Elizabeth Thomlinson from the University of
 Manitoba. The study is supervised by Dr. E. Schilder who may be reached at 474-8202.

I understand that the study will look at the best way to provide services to families of
 children who are slow growers. I know that we have been chosen because my
 child _____ has been diagnosed as a slow grower. The
 other requirements are that I speak English or have an interpreter who is able to explain to
 me what is happening. I live either in Winnipeg, or within two hours driving time of
 Winnipeg.

I was told that my doctor and the nurses on the ward will continue to look after my child.
 Other people will be called on to help us as is needed during the program. Betty
 Thomlinson will visit me at home on 3-4 occasions to find out how everything is going and
 what I feel would be more helpful for ourselves and for other people. These visits will
 take up to one hour a visit. I will be able to decide when these visits will take place.

I know that I may withdraw from the study at any time without affecting the care of my
 child. I realize that my child and family may gain from this coordination of services. I
 also understand that this study is being undertaken to find what should and should not be
 included in a program before it is tried for other children. I have been informed that that
 all information will be kept confidential and that I will not be able to be identified in any
 reports or publications written about the study. I have received a written explanation of the
 study and a copy of this consent.

I know that I may contact Elizabeth (Betty) Thomlinson at _____ or at _____ at any
 time during the study. My signature below indicates my willingness to participate in the
 study.

Date _____

Participant

I would like a summary of the results of this study.

Yes _____ No _____

APPENDIX F

INTERVIEW QUESTIONNAIRE FOR MOTHERS/FAMILIES

For this study I will be asking some general questions about you and your child. Then I wish to ask specific questions about the program.

DEMOGRAPHIC INFORMATION

1. Sex of the child: Male____ Female____
2. What age group:
Newborn to six months____
Six months to one year____
One year to two years____
Two years to five years____
Five years to ten years____
3. Do you have other children? Yes____ No____
if yes, how many?____
4. Do you live in Winnipeg?____ country?____ another town?____

INFORMATION OF THE PROGRAM

5. What do you find about the program that is helpful to you?
Please tell me as much as you can about this.
6. What do you think we could add to improve the program?
Please tell me as much as possible about this.
7. Is there anything we should take away from the program?
Would you explain?
8. What would make this program better for other children and their families?

APPENDIX G

INTERVIEW QUESTIONNAIRE FOR PROFESSIONALS

- 1) For how many children in the program were you on the multidisciplinary team?
- 2) Have you been involved in multidisciplinary care planning for other reasons?
if yes, please elaborate.
- 3) What do you see as the strengths of the program?
- 4) What do you recommend be added to the program?
- 5) What do you recommend be deleted from the program?
- 6) How did you receive your referral to the child?
- 7) Would you suggest any changes in that process?
- 8) Did you receive regular reports of the child's progress?
if yes, did these reports have any impact on your practice?
- 9) Do you see any additional areas of practice where this multidisciplinary approach
may be used?
- 10) Are there any further areas you wish to discuss about the program for children who
are failing to thrive?

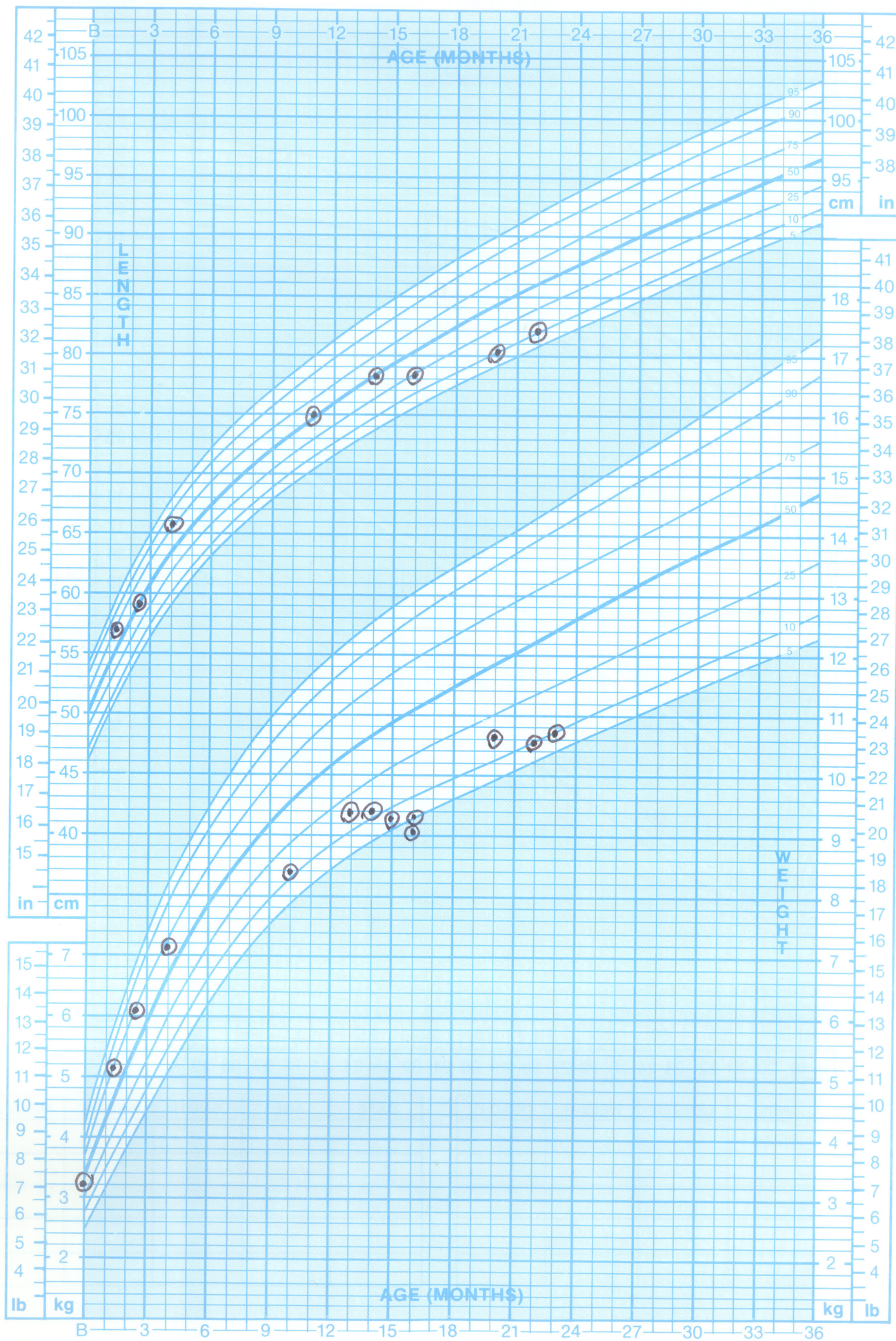
APPENDIX H

BOYS: BIRTH TO 36 MONTHS PHYSICAL GROWTH NCHS PERCENTILES

NAME _____ Child #1

DATE OF BIRTH _____

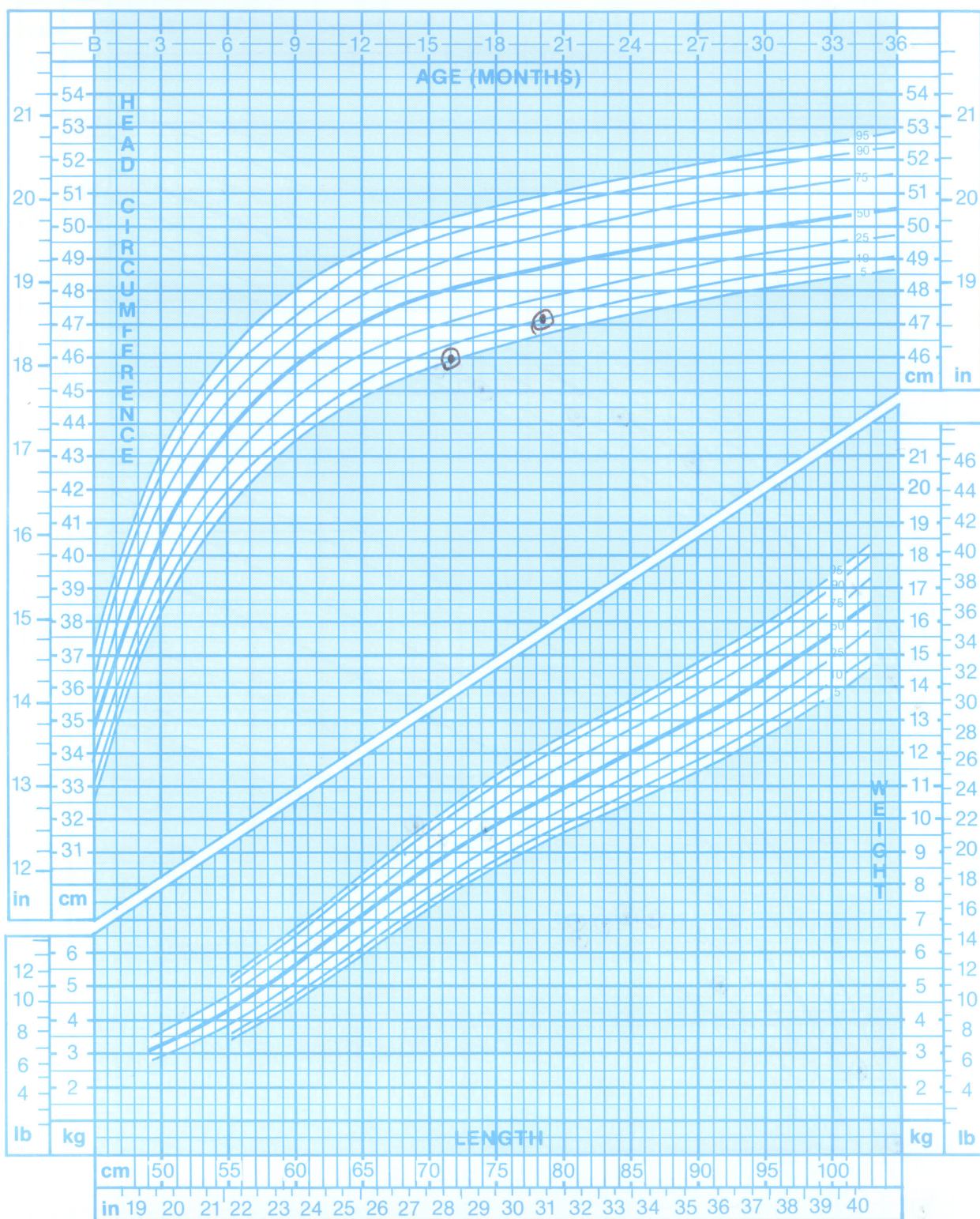
RECORD # 151



BOYS: BIRTH TO 36 MONTHS PHYSICAL GROWTH NCHS PERCENTILES

NAME _____

DATE OF BIRTH _____ RECORD # _____



DATE	AGE	LENGTH	WEIGHT	HEAD C.
	BIRTH			

DATE	AGE	LENGTH	WEIGHT	HEAD C.

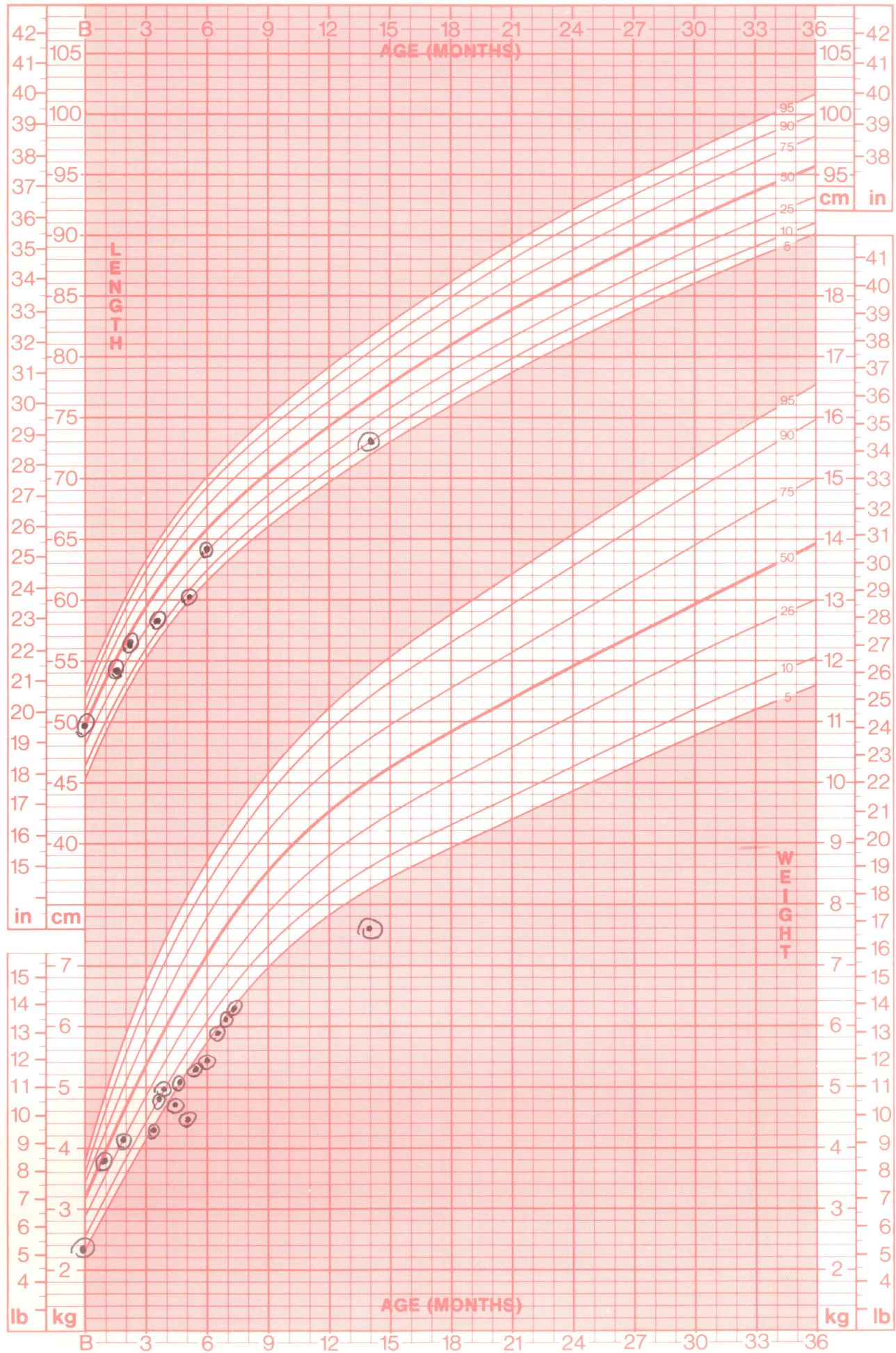
**GIRLS: BIRTH TO 36 MONTHS
PHYSICAL GROWTH
NCHS PERCENTILES[†]**

NAME _____

Child #2

RECORD # _____

152



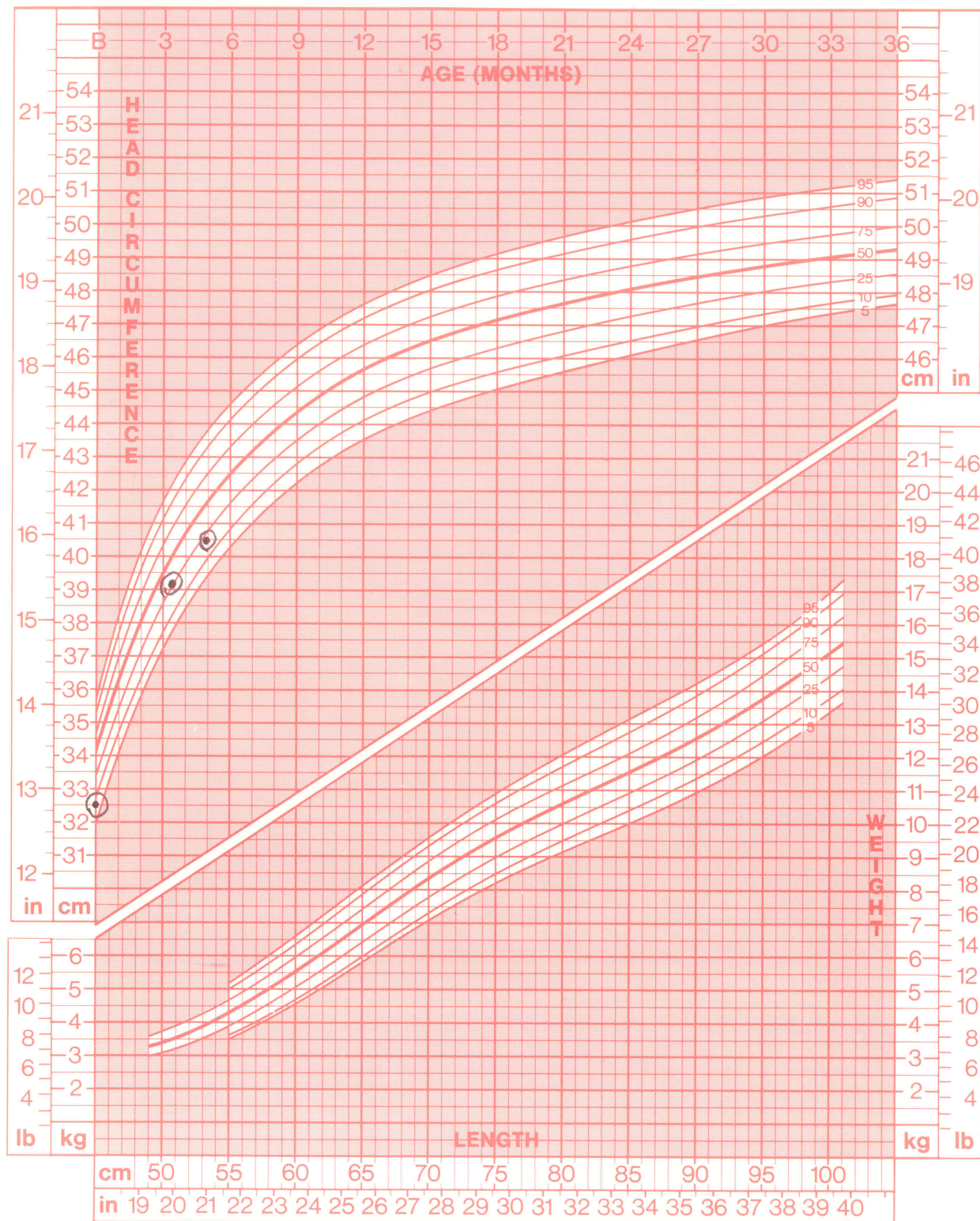
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Ross Laboratories

[†] Adapted from: Hamill PVV, Drizd TA, Johnson CL, Read RB, Roche AF, Moore WM: Physical growth: National Center for Health Statistics percentiles. AM J CLIN NUTR 32:607-629, 1979. Data from the Fels Research Institute, Wright State University School of Medicine, Yellow Springs, Ohio.
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GIRLS: BIRTH TO 36 MONTHS PHYSICAL GROWTH NCHS PERCENTILES[†]

NAME _____

RECORD # _____



[†] Adapted from: Hamill PVV, Drizd TA, Johnson CL, Reed RB, Roche AF, Moore WM: Physical growth: National Center for Health Statistics percentiles. *AM J CLIN NUTR* 32:607-629, 1979. Data from the Fels Research Institute, Wright State University School of Medicine, Yellow Springs, Ohio.

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DATE	AGE	LENGTH	WEIGHT	HEAD C.
	BIRTH			

DATE	AGE	LENGTH	WEIGHT	HEAD C.

SIMILAC*
SIMILAC* WITH WHEY
SIMILAC* WITH IRON
Infant Formulas

ISOMIL*
Milk-Free Formula

ROSS ROSS LABORATORIES
DIVISION OF ABBOTT LABORATORIES, LIMITED
MONTREAL, CANADA

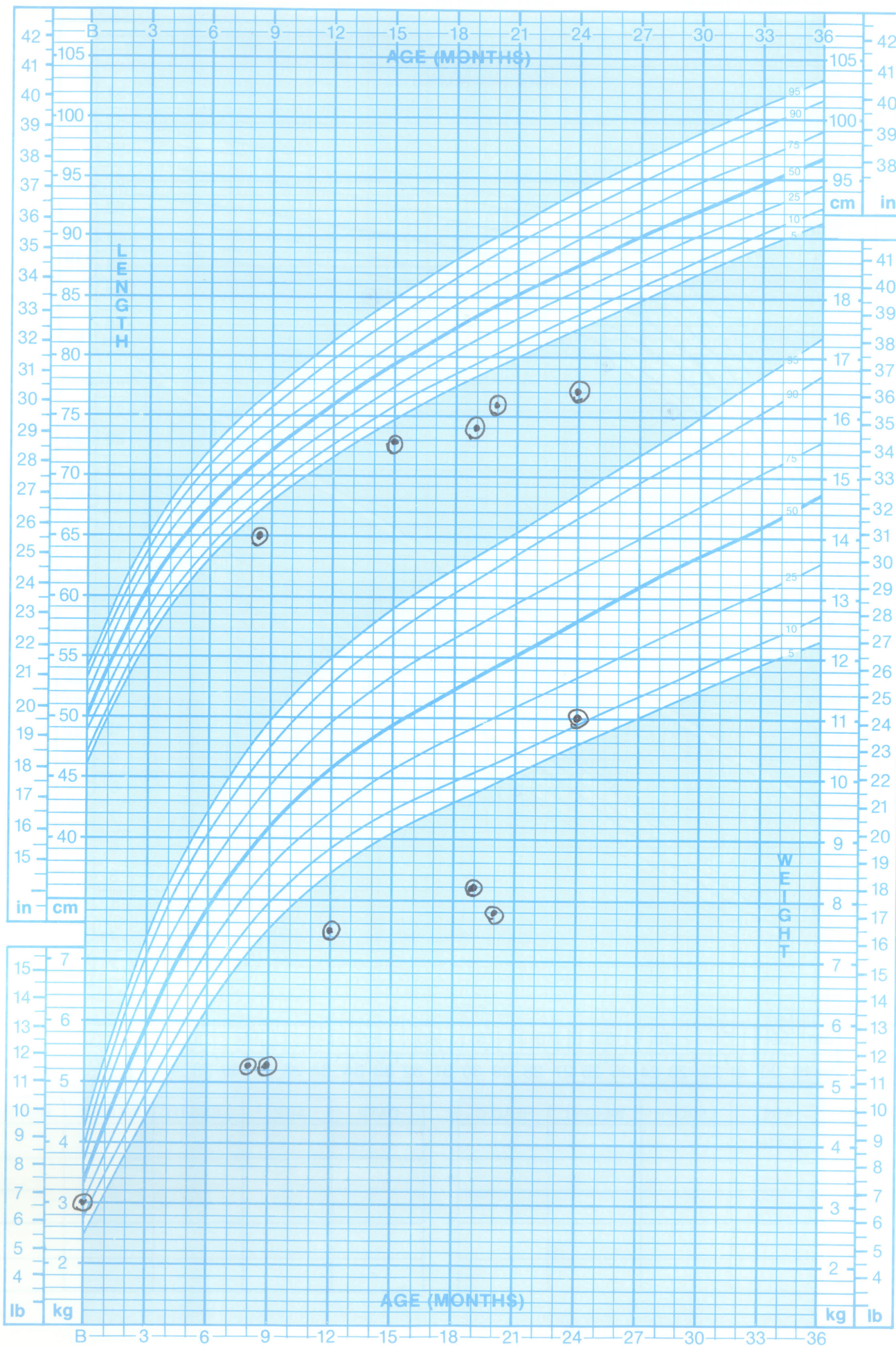
* TM

8062(2)/50ME — Nov. 1986

BOYS: BIRTH TO 36 MONTHS PHYSICAL GROWTH NCHS PERCENTILES

NAME _____ Child #3

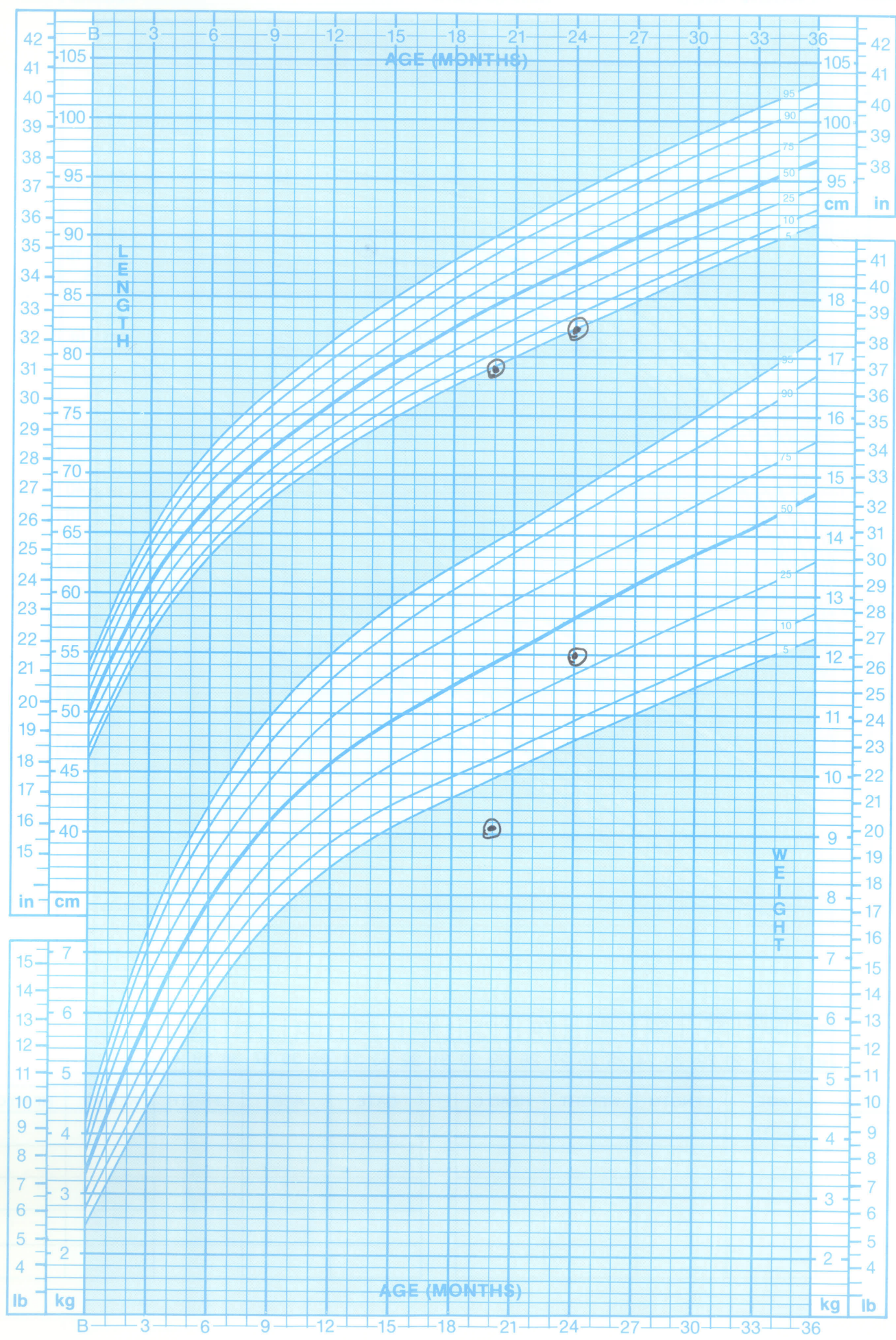
DATE OF BIRTH _____ RECORD # 153



BOYS: BIRTH TO 36 MONTHS
PHYSICAL GROWTH
NCHS PERCENTILES

NAME _____ Sibling Child #3 _____

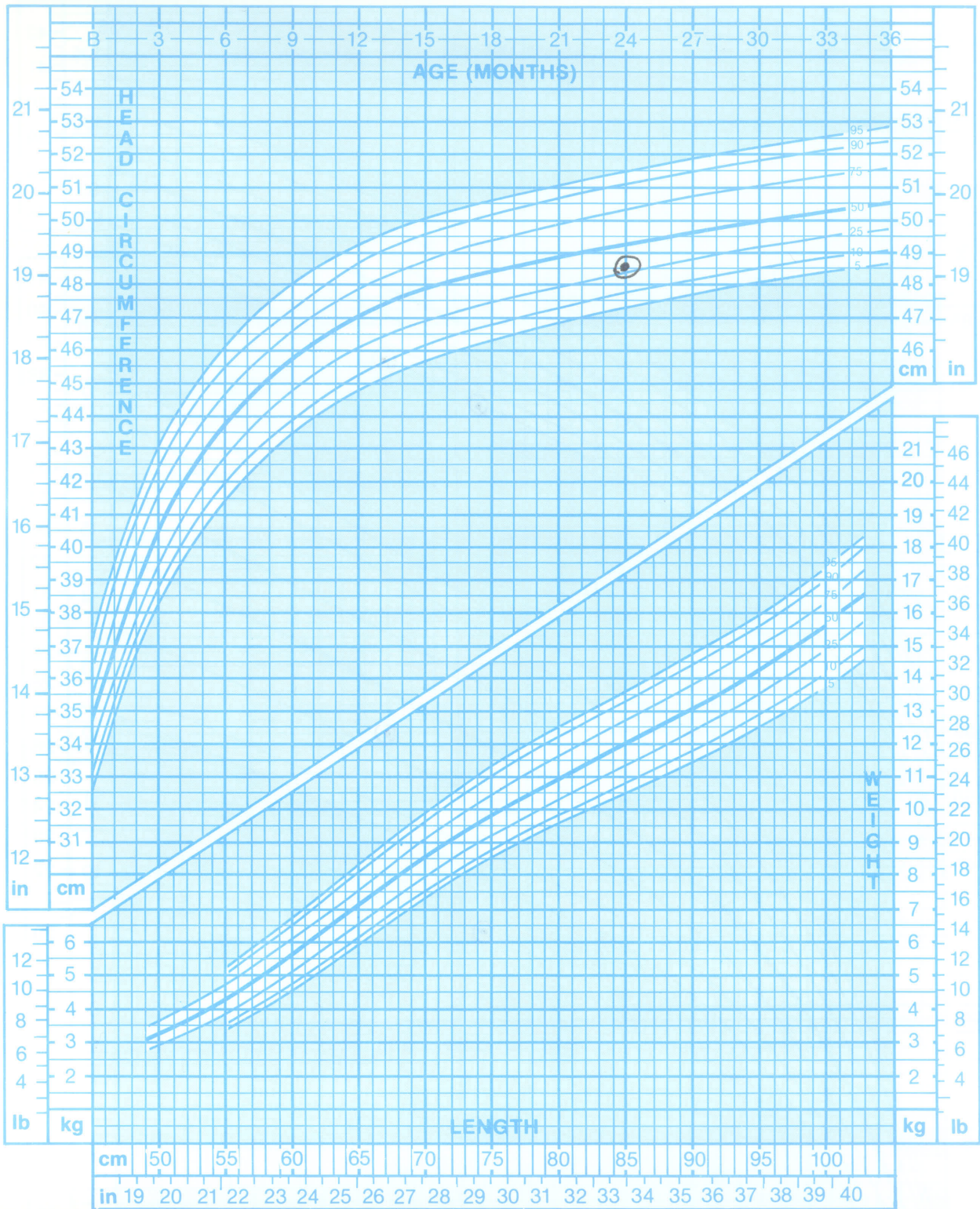
DATE OF BIRTH _____ RECORD # 154



BOYS: BIRTH TO 36 MONTHS PHYSICAL GROWTH NCHS PERCENTILES

NAME _____

DATE OF BIRTH _____ RECORD # _____



DATE	AGE	LENGTH	WEIGHT	HEAD C.
	BIRTH			

DATE	AGE	LENGTH	WEIGHT	HEAD C.

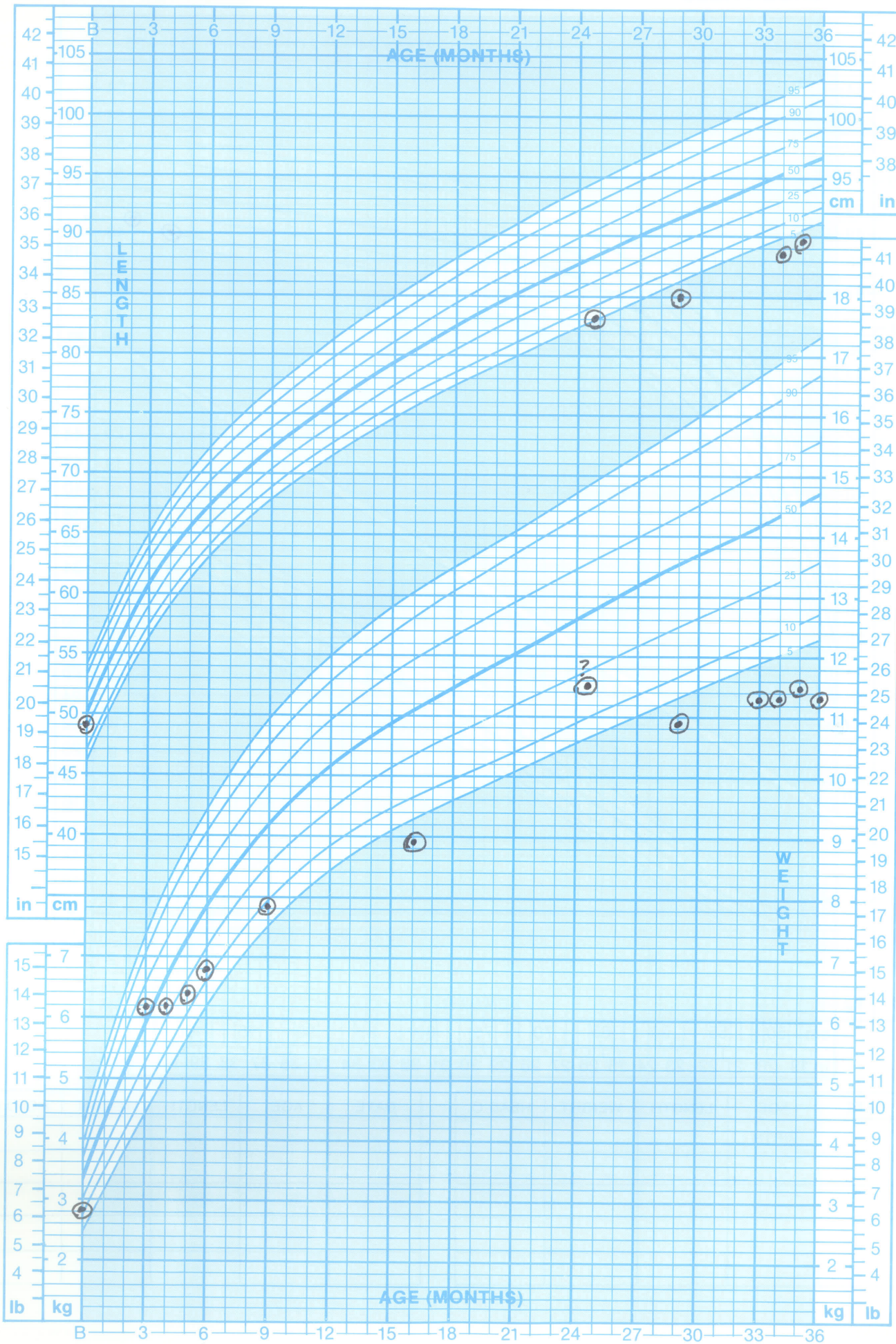
BOYS: BIRTH TO 36 MONTHS PHYSICAL GROWTH NCHS PERCENTILES

NAME _____

Child #4

DATE OF BIRTH _____

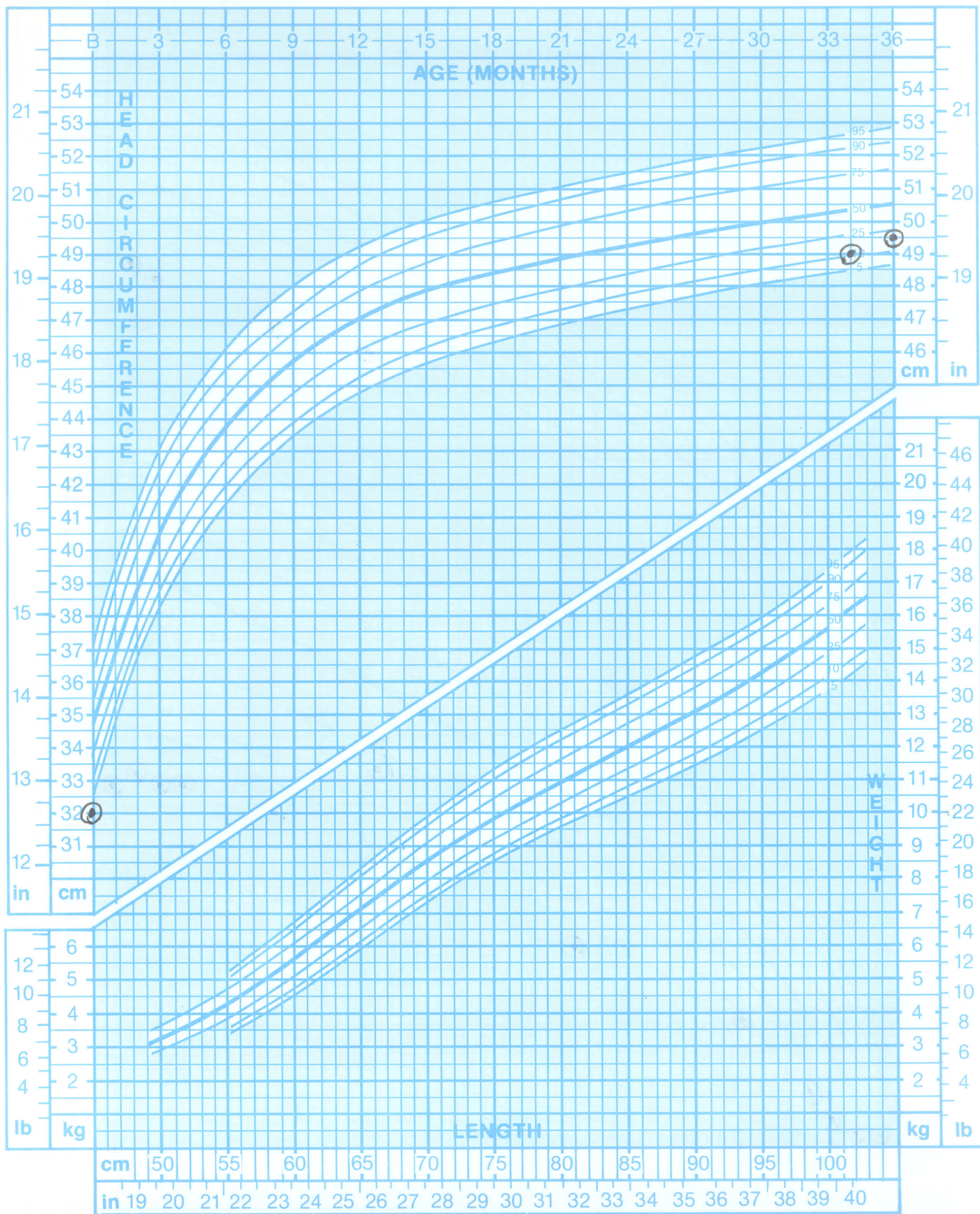
RECORD # 155



BOYS: BIRTH TO 36 MONTHS PHYSICAL GROWTH NCHS PERCENTILES

NAME _____

DATE OF BIRTH _____ RECORD # _____



DATE	AGE	LENGTH	WEIGHT	HEAD C.
	BIRTH			

DATE	AGE	LENGTH	WEIGHT	HEAD C.

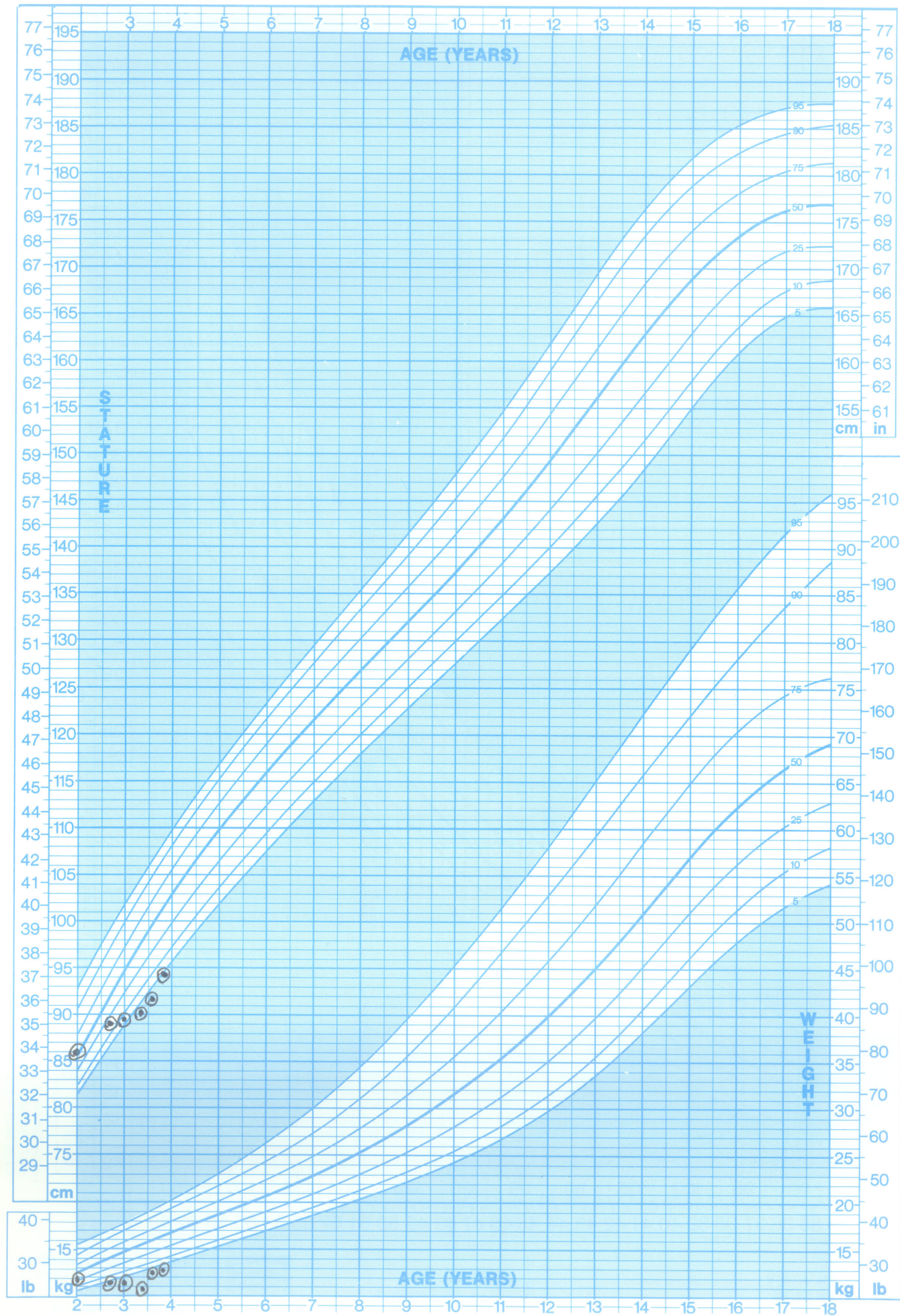
BOYS: 2 TO 18 YEARS PHYSICAL GROWTH NCHS PERCENTILES †

NAME _____

Child #4

RECORD # _____

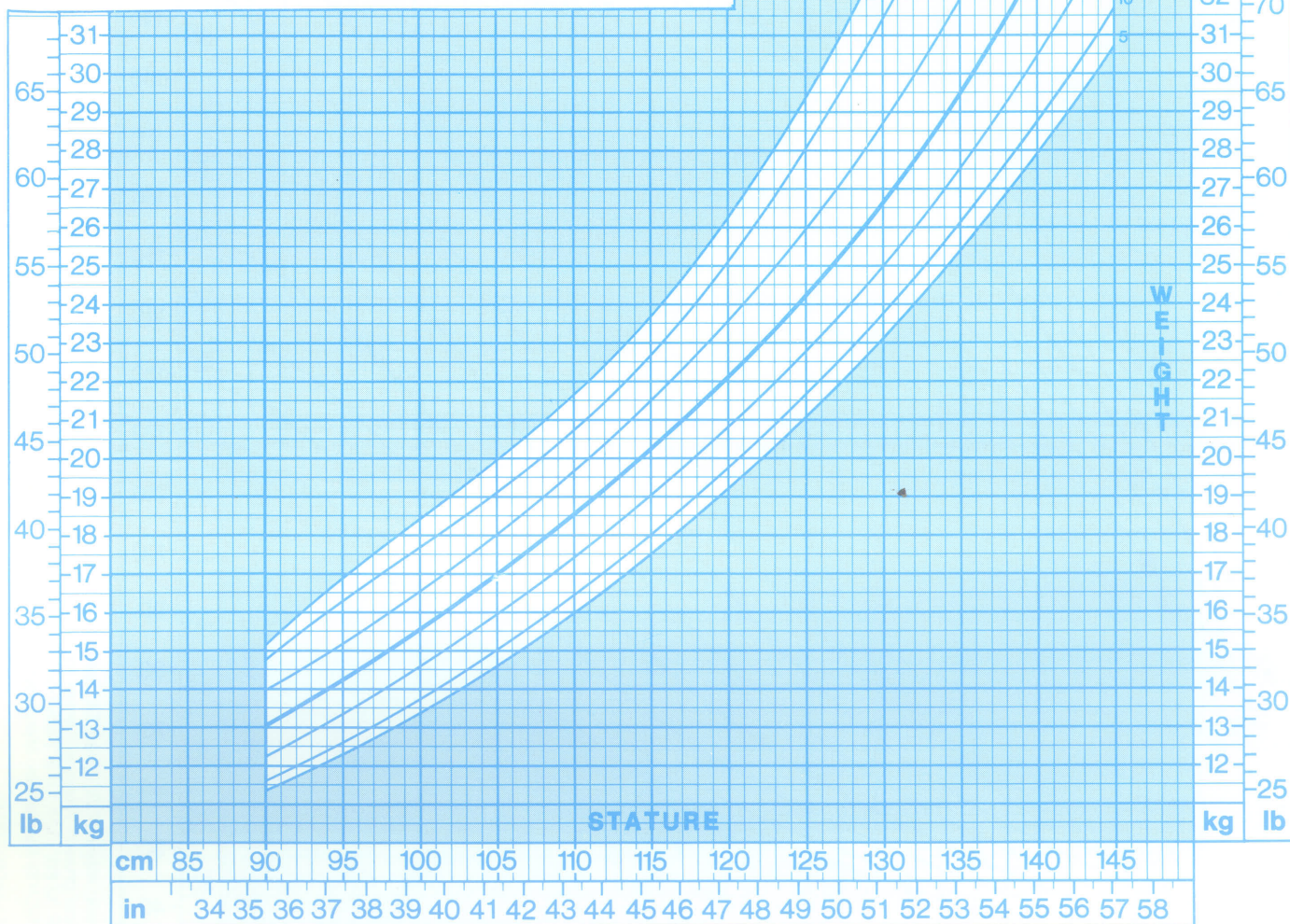
156


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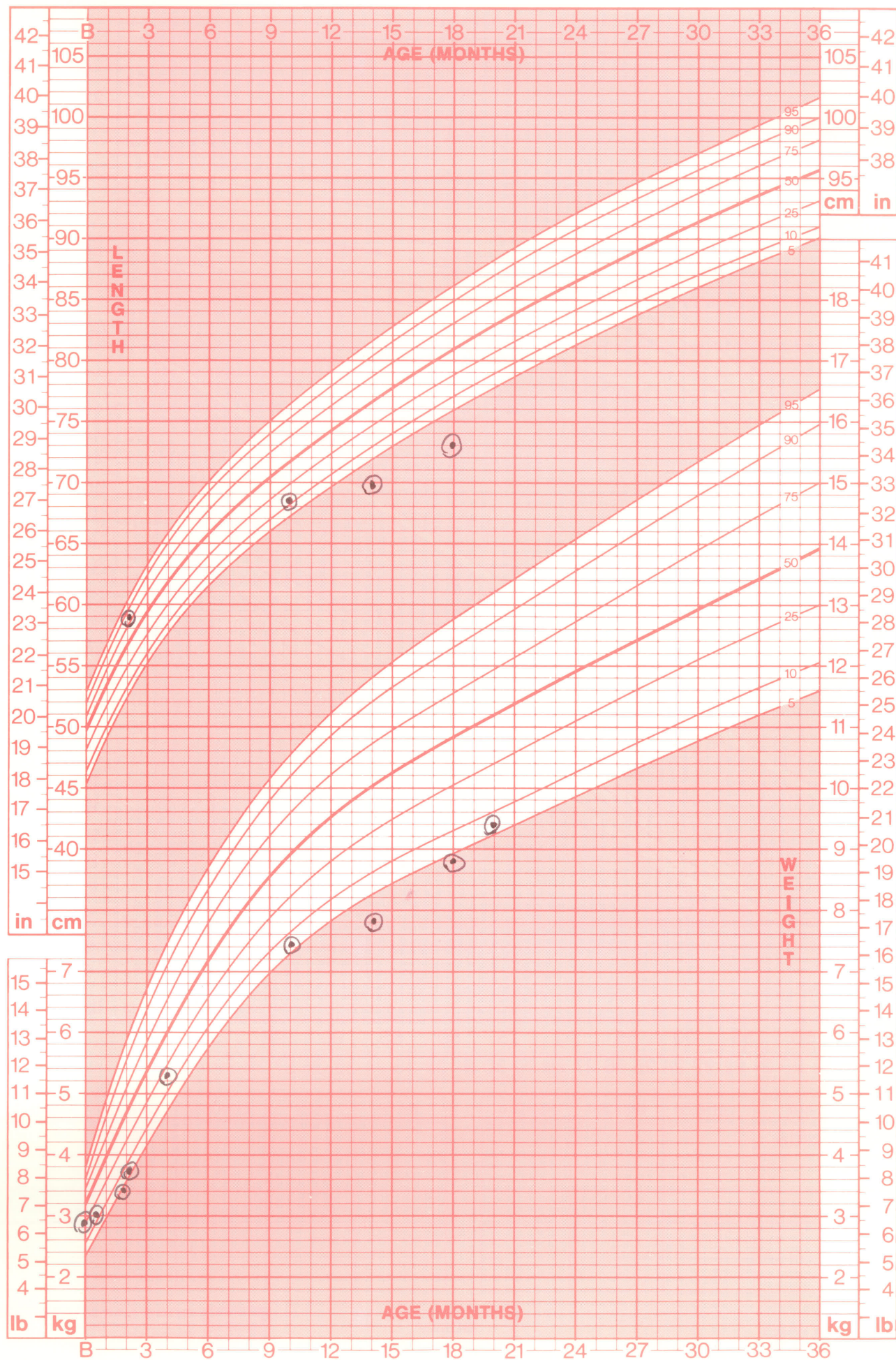
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+ Adapted from: Hamill PVV, Drizd TA, Johnson CL, Reed RB, Roche AF, Moore WM: Physical growth: National Center for Health Statistics percentiles. *AM J CLIN NUTR* 32:607-629, 1979. Data from the National Center for Health Statistics (NCHS) Hyattsville, Maryland

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MONTREAL, CANADA

- TM



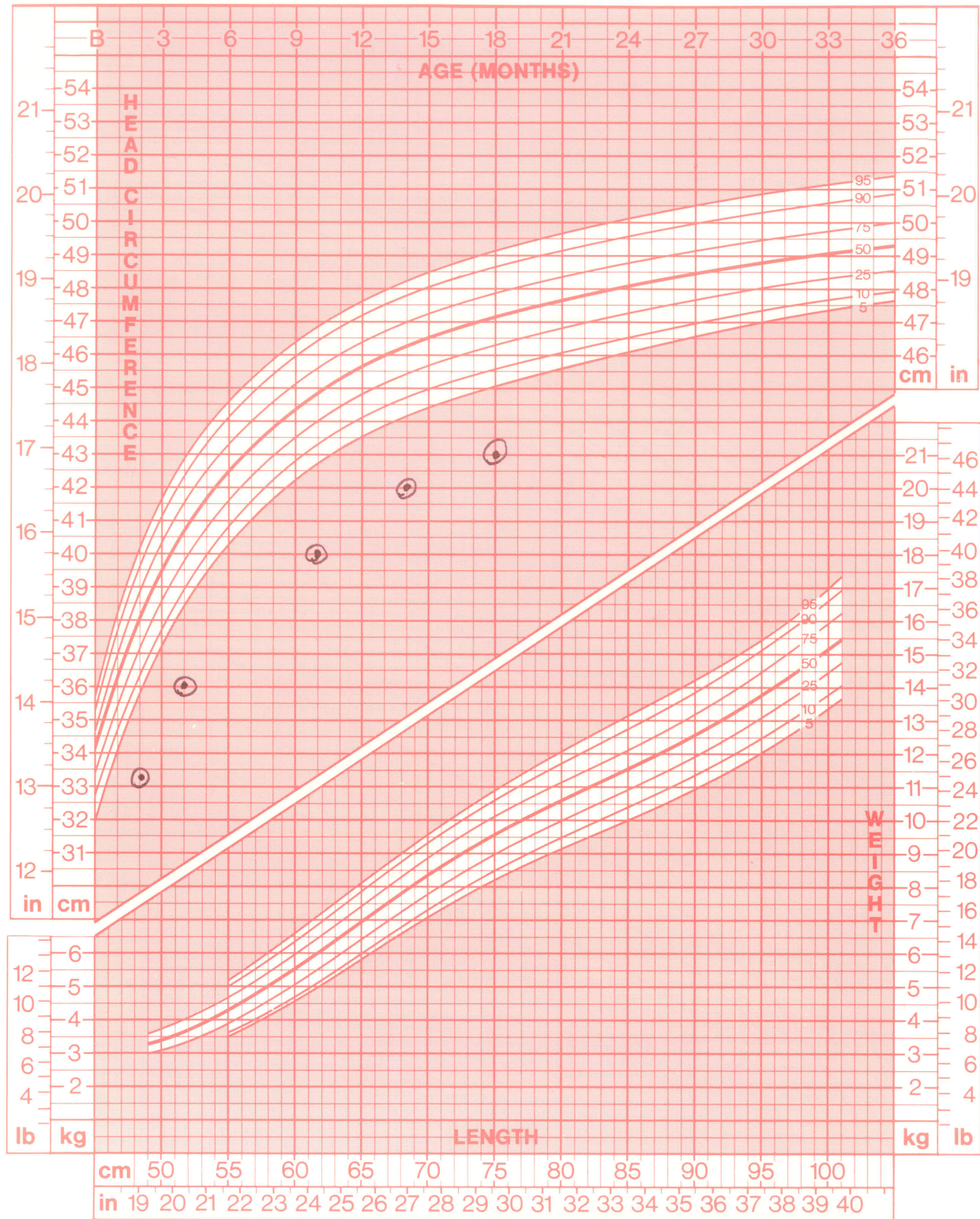
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[†] Adapted from: Hamill PVV, Drizd TA, Johnson CL, Reed RB, Roche AF, Moore WM: Physical growth: National Center for Health Statistics percentiles. AM J CLIN NUTR 32:607-629, 1979. Data from the Fels Research Institute, Wright State University School of Medicine, Yellow Springs, Ohio.

GIRLS: BIRTH TO 36 MONTHS PHYSICAL GROWTH NCHS PERCENTILES[†]

NAME _____

RECORD # _____



[†] Adapted from: Hamill PVV, Drizd TA, Johnson CL, Reed RB, Roche AF, Moore WM: Physical growth: National Center for Health Statistics percentiles. AM J CLIN NUTR 32:607-629, 1979. Data from the Fels Research Institute, Wright State University School of Medicine, Yellow Springs, Ohio.
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DATE	AGE	LENGTH	WEIGHT	HEAD C.
	BIRTH			

DATE	AGE	LENGTH	WEIGHT	HEAD C.

SIMILAC*
SIMILAC* WITH WHEY
SIMILAC* WITH IRON
Infant Formulas

ISOMIL*
Milk-Free Formula

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8062(2)/50ME — Nov. 1986

APPENDIX I

CASE STUDY #1

Child Age 16 Months

Admission to Hospital

This child was admitted on a Friday afternoon for assessment of the cause of the FTT. The child had steadily lost weight over a period of three months. Originally the child, at four months of age, was on the 75th percentile and now was below the 5th percentile. At the time of admission the father was called out of town because of a death in his family. The mother stayed with the child for the entire admission. She was anxious, fearing that the child was suffering a serious disease.

The referral to the study was made on the Monday afternoon after the medical resident had been approached by the researcher. The paediatrician was consulted and gave consent before the resident asked the mother whether she would allow me to speak to her. This meant that it was late on the Monday afternoon when I finally met with the mother. The child was eating his supper, seated in a high chair in his room, with the mother in attendance. Nursing staff had noted that the mother was uncomfortable with the child's attempts to feed himself because he spilled food on the floor. Nursing staff were not present during the feeding when the researcher approached the mother.

The mother had been promised by the physician that the child would be discharged on the Wednesday "once the assessment was done". A one week admission to hospital would have been acceptable to the parents but "...it is ridiculous to admit a child on Friday to sit in all weekend with nothing being done." This promise meant that the proposed research program had to be altered, or the child could not be taken into the study. The study was designed to allow sufficient time in hospital to begin assessment of the child's physical condition and the environment in which he/she lived.

The mother noted that she was not knowledgeable regarding what and how children

should eat and would welcome any assistance possible. Because the researcher did not know about the promised discharge until after the mother had signed the consent, it would have been unethical to withdraw from the family who were anxious to receive help.

Assessment

History

Medical history. The child's medical history revealed six bouts of otitis media requiring medical treatment. In discussion with the mother several explanations were plausible for these infections which are common in children who fail to thrive. A possible cause was the fact that the child drank several bottles of milk each night while lying in bed, allowing flow of fluid up the eustachian tube to the ear.

There was no significant history of medical problems in either of the parent's families. The child's father did suffer from a chronic blood dyscrasia. The child's developmental history, as provided by the mother, noted that the appropriate milestones had been reached within the expected time frames.

Social history. The marital relationship was unstable with the parents separating for a period of six months in the previous year. The father had visited the family and had continuing contact with the child over that time. Since their reunion both parents admitted that the relationship was "rocky" and that this could be affecting the child. The father's parents lived out of town and visited on a regular but infrequent basis. The maternal grandparents who were divorced were each involved in a limited manner with the family.

From five to nine months of age the child had four babysitters as the mother attempted to find adequate child care while she continued to work to support herself and the child. For the past seven months the stability of one sitter had helped establish a routine in the child's life.

Dietary Intake. Although 100 kilocalories per kilogram per day (kcal/kg/day) were required to maintain the child's weight and up to 120 kcal/kg/day were required for weight gain the child ate between 69-126 kcal/kg/day during his admission.

The child had a temper tantrum whenever the mother did not provide him with exactly what he wanted. He threw food on the floor along with his bottle and spilled his glass of juice. Because he was only 16 months of age at the time some of the behaviour could be termed an accident but the actions occurred in response to the mother encouraging the child to eat or when he wanted something (a bottle of juice) which was not immediately forthcoming. When the mother was speaking to the researcher during the child's feeding he promptly threw his spoon on the floor in an apparent attempt to focus attention on himself.

The dietitian met with the mother to provide advice on what foods to introduce into the diet of a 16 month old who is learning to control a spoon and feed himself. Finger foods, puddings, and other milk products were suggested as one means of providing additional calories. The current level of 8-10 bottles of juice and milk a day was to be decreased to no more the 4-5 daily. The child was receiving the largest percentage of his daily caloric intake from the fluids in his diet.

Detailed assessment of the mother/parent/child interaction during meals was not available over the four full days of admission. The researcher was available for two supper meal times and answered questions posed by the mother. I was able to role model some responses when the child became angry and "had a tantrum" during his meal.

Tests. This child had a barium swallow as an outpatient prior to admission to determine whether there were any abnormalities in his gastrointestinal tract. In hospital the only tests run were a complete blood count and a urinalysis (Table 2). The results of these tests were within normal ranges. The limiting of tests until the parent/child interaction and

feeding assessments had been conducted is in keeping with the studies conducted in other countries.

Developmental assessment. The child was assessed at, and above normal, in various aspects of the developmental testing. Movement, coordination, and ability to comprehend were some of the skills assessed. The mother assisted in the developmental testing and provided the physician with a history of the child's development. The mother identified that stresses in the home had resulted in the child using food to control the situation.

Psychosocial assessment. One of the social workers who conduct assessments for the Child Protection Centre at Children's Hospital was asked to interview the parents for a psychosocial assessment. Initially the mother displayed fear at the request that the worker be allowed to speak with her. Following an explanation that these workers were not connected to a child welfare agency with powers to apprehend children, the mother agreed to meet with the worker. Because of the impending discharge of the child from hospital the worker arranged to interview the parents at home early one evening.

The mother mentioned her own mother on various occasions noting their relationship was tenuous at best. The mother believed that her own mother denigrated her skills as a person and a mother. The grandmother did not think that the child's father was adequate and that the mother and father should never have reconciled. Mother #1 throughout her conversations would then belittle her own efforts as a parent and comment disparagingly about her abilities as a wife and mother.

The Admission

The child was slight of build with his ribs visible when he was not dressed. He was constantly moving, touching and exploring. When he touched a ward cart and I cautioned him about it he quickly withdrew his hand. The mother noted that she did not

move any of the ornaments in the home and the child was expected to leave them alone. By talking about developmental stages of a child's growth parental expectations and tasks were emphasized and realistic expectations for children were considered. Child #1 maintained appropriate distances from the staff and researcher and would cuddle into his mother's arms. He pretended to drive the play car and made sounds to portray a car running. His vocabulary consisted of six to seven words, dependent on one's ability to understand him.

Throughout the child's admission, although the mother noted inconsistencies in the child's care, she excused the nursing staff by saying "they are so busy". One morning this child ate his breakfast only to have the mother told that he should have been weighed first. The next morning she asked about having him weighed but decided to feed him after one half hour when no one came to weigh him. This mother was hesitant to ask for a bottle for the child at bedtime as she believed that the nurses disapproved of giving him one. She could not identify what prompted her to believe this other than body language displayed by the nurses when she asked.

Parent/child interactions were not recorded during the admission. The mother and child spent time off the unit in the cafeteria and in the parents' room on the floor. The mother was anxious about the amount of time she was having to be away from work although her employer was being supportive. Following the child's developmental assessment and the establishment of follow up appointments the child was discharged mid week.

Follow Up Appointments

The social worker visited at the family home for one interview with both parents present. She was able to begin preliminary discussion on parental interactions, strengths and

needs. The parents were unable to keep the next scheduled appointment but the mother did attend at the social worker's office on one occasion after work. The mother stated that she was too tired to meet after work and although she commented that she was aware of the difficulties in the marriage she did not have the energy to confront the problems. The father did not attend any further meetings.

The researcher visited in the home on five occasions over the period of seven months. On the first two visits the mother noted that she was tired as she was pregnant and expecting their second child. A minor crisis arose when the original babysitter was unable to continue because of being in the later stages of her own pregnancy. Family Services Incorporated attempted to find a placement within the geographic area. Unfortunately, because the mother's own pregnancy was unstable it was decided that she would not be able to provide the two weeks notice required before terminating service from an agency day care. Therefore, a sitter acceptable to both the child and parents was found within a short distance from the home that did not have this stipulation.

The low birth weight of the twins did not allow them to be discharged postnatally with the mother. The mother used public transportation to visit the children who had to remain in hospital to achieve a weight of over four pounds prior to discharge. The availability of a homemaker facilitated the visits and, except for one week when the children's paternal grandmother visited, this person was in the home daily for two months.

Over the seven months I communicated with the mother by phone seven to eight times answering questions, attempting to assist with babysitter arrangements, and providing reassurance and consultation. The marital relationship remained unstable with the father threatening to separate on several occasions. The mother was aware of the father's strengths but was unable to acknowledge them to him. She stated that in the past she had always been disappointed by "people" and continued to expect that would happen. In the presence

of the father the mother articulated that it was difficult to trust anyone; a statement that he did not acknowledge. On no occasion did the researcher meet with the father alone. He did not wish to meet with the social worker following the initial interview.

The child gained weight over the period to the 10th percentile, while he continued to achieve all his developmental milestones. He attempted to revert to his former eating habits after the twins had been home for one to two months. His meal patterns were discussed with the dietitian who encouraged limiting his fluid intake (which had again increased) and offering nutritious high calorie snacks between meals.

APPENDIX J

CASE STUDY #2

Child Aged 6 Months

Admission to Hospital

This child was admitted to hospital in the attempt to determine the cause of an "inadequate intake". This was the first and only child of a couple who had immigrated to Canada more than four years ago. The baby had been born by vertex presentation at 36+ weeks gestation. However, the mother had required a hysterectomy immediately post delivery because of serious medical complications. At birth the child had been at the 5th percentile for weight, the 25th for height and between the 5th and 10th for head circumference.

At the time of the intake the child was below the 5th percentile for weight, at the 25th for height and on the 25th percentile for head circumference. The child was thin but not emaciated with a serious expressionless face. She responded to interactions from the hospital staff. The mother remained in hospital throughout what proved to be a short admission.

The child was admitted on a Friday afternoon for assessment. The family was referred to the study on the Saturday but they were not seen until Monday. While the researcher went to obtain the study consent form the child was discharged from hospital. The physician suggested that an outpatient contact would be a means of enrolling the family into the study. After much consideration and discussion with a nurse at the Child Protection Centre it was decided that, rather than exclude this child, a follow up on an outpatient basis may be valuable. The family had been approached prior to leaving hospital and agreed to have the researcher visit at home.

The parents both read and write English but have some difficulty expressing themselves, although they never demonstrated problems understanding what the researcher

said. A copy of the explanation of the study was left with them to enable the father and mother to discuss privately whether they wanted to enrol.

Assessment

History

Medical history. By three months of age the child had fallen off her percentile curve and was admitted for colic and FTT when her weight reached the 5th percentile. In hospital her fluid intake was sufficient to prompt a quick response in weight gain. The discharge plan at that time was to have the physician continue close medical follow up while the public health nurse made regular teaching home visits. The mother believed that the baby's stomach was "not normal" because she 'burped too much'. The child was fed by the clock four ounces at one time to prevent her from becoming too fat. The child was otherwise well.

Social history. The father had originally immigrated to Canada while the mother had remained with her family. After two years she had followed him to another city in the province where they lived for several years. They had relocated to Winnipeg because of the father's work. He was attending a trade school for several months a year to learn a trade. The mother had worked as a seamstress until the delivery of the baby. Both parents had been professionals in their home country.

Neither parent had any family members in this city although the father had brothers in another city in Canada. The mother stated she had some friends in Winnipeg who lived within a reasonable distance of them. Some family members lived in other countries of the world while the majority of her siblings remained in their home country. She often spoke of how homesick she felt.

Dietary intake. This child required up to 120 kcal/kg/day of food to begin to gain weight. The public health nurse had stated that she had encouraged a limited amount of baby cereal for child #2. The mother, upon reading that the cereals were enriched with iron, refused to give the child any stating the iron gave the child diarrhoea. No amount of information could sway this mother from this belief.

The child drank her bottle well, was slow to burp, and then would settle to sleep. The mother appeared annoyed when the child did not burp when she thought she should. The mother would not refrain from touching the child and moving her while she was asleep. The child was fed her bottle while lying loosely lying in her mother's arms and was not cuddled at all while feeding. Nursing staff documented their efforts to role model bottle feeding behaviours for the mother. They noted that she became visibly upset if the child was allowed to drink more than four ounces at a feeding.

The mother did not appear relaxed at any time during the admission and remained tense. She interpreted regurgitations that the baby had often after feeds as vomiting. The mother would then proceed to bounce the child in her arms immediately following her feeding. An interpreter at the hospital spoke with the mother to ensure that there was no misunderstanding of the attempted teachings because of the language barrier.

A referral was made to the dietitian on the day (Friday) the child was admitted to hospital. On the following Monday morning when the dietitian arrived on the ward to consult with the mother the child had been discharged. A daily caloric count of the child's intake during hospitalization determined that she drank 110 kcal/kg/day; an amount adequate to maintain growth. An appointment was arranged with the mother but she did not come to the dietitian's office nor did she phone to cancel.

Tests. On the first admission to hospital two months previously, an abdominal ultrasound, stool tests for bacteria and parasites, a complete blood count and differential

(CBC & diff), and the blood electrolytes were performed. On this admission the CBC was the only test done.

Developmental assessment. The paediatrician determined this child was achieving her appropriate milestones at six months of age, therefore developmental testing was not done. The child would lift her trunk on her arms when prone, could roll over and would hold her bottle if the mother was encouraged to allow her. She would coo and make other babbling sounds spontaneously and in response to face to face interaction.

Psychosocial assessment. The social workers of the Child Protection Centre were unable to begin a psychosocial assessment of the family because: a) the child was discharged prior to any opportunity to contact the family, and b) the parents were not willing to meet with the worker. They expressed this by avoiding the subject when it was broached and by saying the child was sick on the day an appointment was made to attend at the Centre.

Follow Up Appointments

The researcher spoke with the public health nurse who had been regularly visiting the mother and child every one to two weeks. She described the same concerns the nursing staff expressed about the apparent inappropriateness of mother/child interaction. The nurse's attempts to interest the mother in visiting The Young Parents day centre where the mother and child would interact with other young mothers and their children had been unsuccessful. Eventually the mother did visit the centre on two occasions, once with the public health nurse and once with the researcher. Although the centre offered to provide transportation for other visits the mother did not wish to attend despite the fact she showed great interest in what was happening when she was there.

The researcher visited nine times in the home and was in contact by telephone on

seven to eight other occasions. Three visits the mother cancelled saying the child or she herself was ill and had gone to the doctor. On one occasion each the public health nurse and the researcher suspected that the mother was in the apartment but would not answer the doorbell.

At alternative times one of three public health nurses, dependent on assignment of caseload as others were on holiday or leave, used the home visiting time to teach about diets and normal child growth and development. On these home visits the mother talked about her youth, her family, the difficult role of women in her native country, and the differences in Canada. The mother continued to speak sharply to the child if she fussed or cried while the researcher was in the home. She stated her child was "bad", not like her friend's daughter who drank well, slept, and was growing at a faster rate.

As both the public health nurse and the researcher were conscious of cultural needs and differences a counsellor from the Immigrant Women's Association was introduced to the family. This association serves as a resource centre, a social centre, offers classes in English to immigrant women, and provides counselling services to families who wish to access their services. The mother became animated when speaking in her native language to the interpreter and to the counsellor.

The family moved into a larger apartment in the same building which allowed the child to move freely about the rooms. On the final visit the child was attempting to take steps, was eating both canned baby foods and mashed foods the mother prepared, attempting words, and was between the 5th and 10th percentile for height and remained below the 5th percentile for weight. Her fine and gross motor skills were appropriate for her age. She did however, often go to her mother to be held and carried. The mother continued to speak of her loneliness, her wish to see her family, and her desire to return to work. The counsellor from the Immigrant Women's Association knowing of the termination of the

research study stated she would continue working with the family. The public health nurse's time was limited by the extensive caseload she carried and she did not anticipate continuing contact with this family.

APPENDIX K

CASE STUDY #3

Aged 19 Months

Admission to Hospital

This 19 month old boy had been seen three times for developmental testing at the Child Development Clinic following admission for FTT at eight months of age. At birth the child was on the 10th percentile for weight. Child #3 was one of a twin birth at 38 weeks gestation with apgar ratings of 9 at 1 and 5 minutes. Community resources assisting this child and family were the child welfare agency and infant stimulation workers. The mother received social assistance as she was a single parent of three children.

The child was admitted to hospital for further study of ongoing growth failure and delayed developmental milestones. The paediatrician wished to test for zinc levels and start zinc therapy if test results determined that necessary.

The researcher had been notified of the admission prior to the arrival of the child but was unable to approach the mother at that time because she first had to decide whether she was willing to meet with the researcher. The mother contacted the researcher the following day and arrangements were made to meet her at the hospital that evening. After an explanation the mother agreed to participate in the pilot study. The mother did not have a telephone nor did she have transportation to the hospital other than with friends. Public transportation was difficult to access from the area of the city in which she lived.

Assessment

History

Medical history. The child and his siblings received medical follow up approximately every four to five months throughout the year previous to admission. On the child's past admission for investigation of FTT there were no findings other than a mild

delay in bone age and nonorganic FTT. Both parents were well; there was no history of a major illness in either family.

Social history. The parents separated when the youngest children were four months of age. The father had not visited and did not support the family following the separation. The mother stated the separation had occurred because the father felt that he came second to the children and was unable to "come between me and ____ (child #3)".

The maternal grandparents had frequent contact with the family as the older sibling spent each weekend with them. They provided some assistance by purchasing clothing for the children and occasionally buying food for the mother. The paternal grandparents were not involved with the family.

The mother spoke of several friends who lived in the same complex and of others who lived in different areas of the city. She stated that she had a 'friend' who would bring movies on the weekend so they could stay home and care for the children. She emphasized that she did not wish to leave the children but, if she wanted the respite sitter would care for the children. She would not answer any questions regarding the frequency of accessing this service. The researcher was able to determine that this sitter service had not been used by the mother.

Dietary intake. The child would hold finger foods such as toast and cookies to eat. He was in the process of learning to use a spoon but would not feed himself his cereal on admission. He drank well from a feeding cup.

Starting from the day of admission this child ate between 119-200 kilocalories /kilogram/day (kcal/kg/day). This was well in excess of the 120 kcal/kg/day required to stimulate growth. Average daily weight gain for 19-20 month old children is 7 grams per day. Over the two week period of admission child #3 gained 65 grams per day. Originally he ate ravenously but by the end of the two week period his intake had moderated.

There was no opportunity to assess the mother/child interaction as the mother visited three times for 3/4-1 hour each time during the admission. The visits did not coincide with meal times. Nursing staff and physicians stressed to the mother the value in frequent visiting for longer periods of time.

Description of the child. On admission to hospital the child sat silently in his crib. He was apathetic. He would crawl commando fashion and occasionally would pull himself to stand in his crib but would not weight bear if held. He would immediately draw up his legs if one attempted to have him stand. He spent time in his crib rocking on his hands and knees or sitting with his legs through the crib rails rocking. The child was indiscriminate and would allow anyone to pick him up. He would attach to the latest person to hold him.

The child was very fair, with alabaster skin and thin wispy blonde hair. His pallor and petite stature prompted medical and nursing staff to assert that there "...had to be more than FTT wrong with this child". His skin was dry and scaly with cradle cap on the back of his head and behind his ears. He rarely smiled but would cling to any person who held him. Once while the researcher was observing, the child crawled to the mother of another patient wanting to be picked up.

Tests. Multiple tests were conducted as medical personnel continued to believed that the child must be suffering from some yet undiagnosed disease. These tests included: a bone age X-ray, oximetry, audiometry, a complete blood count (CBC), electrolytes, creatinine, urea, total carbon dioxide, serum zinc, urine and blood for metabolic screen, serum calcium, serum phosphate, and alkaline phosphatase. All test results were within normal ranges.

Developmental assessment. Prior to admission the child had on developmental testing performed at levels between 8-13 months of age. Although there is variability in

each child's development this was well below the expectations for this child's age. In all aspects of testing, fine and gross motor skills, language understanding, and speech the child's successes were well below those expected for his age.

Psychosocial assessment. The mother maintained that there was nothing unusual about her child's development and therefore refused to meet with the physician. Although appointments were made with the social worker at the Child Protection Centre for assessment, these were not kept. Therefore, an in-depth understanding of the mother/family was not available to assist in the decision of what services would be most effective to help the family.

A meeting of all the professionals involved with the family attempted to provide an evaluation of the services necessary to help the child grow and develop.

The Admission

Initially, the child ate voraciously whenever he was given food. Throughout his admission he screamed when the nursing staff attempted to bath him. Originally the staff were unable to produce a change in the child's affect, but eventually he began to respond to the staff's overtures. The child life worker took him daily to the playroom to further stimulate him. He would smile and respond to their attempts to interact with him. The child remained quiet however, and still did not respond verbally with sounds nor with words after the two week period.

Two weeks after admission the child was developmentally assessed by another physician at which time it was concluded that he had shown marked improvement in his development to the 18-19 month age level. This demonstrated that the child was capable of rapid change in behaviour in a changed environment.

Two team meetings that included 10 disciplines and services, attempted to formulate

a long-term plan of care to best benefit the child and family. The mother was not invited to attend these meetings but the discussions were relayed to her by the child welfare worker.

Follow Up Appointments

The social worker was to visit on a regular basis and ensure that the parent aide was in place at least three days a week to assist the mother in meal planning and in shopping. Assistance with budgeting and meal planning was provided through community services. Appointments were made with the physician and for developmental testing on days when the parent aide was available to go with the mother.

There had been agreement between the professionals at the team meeting that an in-depth psychosocial assessment was necessary to determine the most effective methods for assisting this family. The contract between the mother and the child and family services worker stated the mother was to meet with the assessment worker. This worker was present for the first interview while babysitting service was provided for the mother. The mother attended one other interview and the assessment worker then went to the home during a meal time to view the parent/child(ren) interaction. The mother however, refused to attend a final interview with the assessment worker and the child welfare agency worker determined that she did not have to meet the contract. The child welfare agency worker did not discuss this with the other team members, nor with the assessment worker.

The researcher visited in the home two weeks following discharge of the child from hospital. The mother showed little affect initially, but when asked what the problem was, she began to cry stating that she did not believe that she could be so hurt and alone at her age. During the visit she spoke of her difficulties in raising the children alone and of her desire to move to another area of the city. She stated that she would move at the end of

the month. However, when the researcher attempted to make a home visit later in the month the family had already moved. Because the family did not have a phone the researcher was unable to contact them. After obtaining the address from the social worker the researcher again attempted to make a home visit but received no response. The social worker then asked the mother to contact the researcher and a home visit was arranged. During this afternoon visit the parent aide was present but the children were in their beds although the older child did ask to be allowed to get up. The other two children could be heard in their bedroom but during the hour and fifteen minute visit they were not brought out of their room. When the researcher asked to see the children she found the two children sitting, clad only in diapers, in their cribs with no sheets or blankets in the cribs.

A future home visit was cancelled by the mother an hour before the scheduled appointment at which point she informed the researcher she no longer wished to participate. The researcher did attend three further meetings between child welfare and health care workers. At the first of these meetings the parent aide stated she had been informed by the mother she would no longer allow her into the home. The child welfare agency also transferred the case to a new social worker in another agency. In five months all the professionals, except those at the Child Protection Centre, had changed. The mother had changed paediatricians as soon as the child was discharged from hospital.

At the time of the latest meeting, eight months after intake, there was discussion about a suggestion from the mother that she would be moving again. The social worker shared the information that the mother was planning what she would purchase with her child tax credit refund. On the social worker's latest visit, Mother #3 had apparently been discussing with a tax person by phone how to obtain this money. The researcher informed the social worker that according to the previous parent aide the mother had received and spent within one week in November her entire tax credit. The parent aide was to continue

attending in the home three times weekly, with supervision and follow up by the social worker. The child and one sibling were to have repeat developmental testing to assess progress. The mother continued to deny that any problems existed and did not appear receptive to visits in the home by any of the support workers.

APPENDIX L

CASE STUDY #4

Aged 37 Months

Initial Contact

Mother #4 first brought this child to the Child Protection Centre (CPC) when he had been beaten by a baby-sitter when she was out of the home one evening. She expressed concerns that the child welfare authorities might "...take my child away from me". Child #4 was examined by a physician and with encouragement from the social worker at CPC the mother reported the incident to the child welfare agency. She took steps to ensure the safety of the child following this episode.

Concurrently the mother was bringing the child to the Children's Clinic for regular medical follow up and for investigation of his slow growth. A developmental assessment had been scheduled prior to the incident, coincidentally with the same physician who had seen the child the week previous to examine his bruising. The researcher had received a referral from Children's Clinic regarding the child. A request was made that the researcher be allowed to view the assessment through the two-way mirror, to which the mother agreed. Following this the mother was given an explanation of the study and an appointment made to visit in the home.

During the home visit the researcher observed that the child was very busy, constantly moving about the room and riding a tricycle down the hall. The mother had an old couch in the living room specifically on which the child could play. When he wanted to get up on the other furniture he sat, albeit for short periods, after which he was up running. The mother stated that she felt he was too small for his age and was not growing as he should. She noted that the physician had suggested a short admission to hospital for investigation. The physician wished to determine whether the child would, in a controlled environment where his intake was closely monitored, gain weight. The mother asked the

researcher to ascertain how quickly this could be arranged and followed this up by a call to the researcher's home.

The mother expressed that she was happy when admission to hospital was arranged for the following week. Although she lived within several blocks of the hospital the mother slept in the child's room and would go home for brief periods during the day while the child was sleeping or when he was in the main playroom.

Assessment

History

Medical history. The child was the first and only child born to this mother. Both parents were well with no medical problems. Within the immediate families both cancer and diabetes were present. The pregnancy was full term with no complications and both the pregnancy and the delivery presented no complications. At birth, child #4 was at the 10th percentile for weight and the 25th percentile for height.

The child had been followed by the family physician in the former area in which they lived. This physician had noted the child's small stature but had conducted no investigations. The child had suffered several bouts of otitis media, tonsillitis, and diarrhoea to the time of admission.

Social history. The mother was the sole caretaker of this child as she had requested the father leave when he had an affair with another woman. In conversation with a child life worker, the father stated that he visited weekly but the mother denied that he maintained this amount of contact. The mother took the child to visit both the maternal and the paternal grandparents infrequently. The mother received social assistance but expressed the desire, once the child was in school, to upgrade her education and obtain employment.

Dietary intake. The child at three years of age could feed himself and had preferences and dislikes for specific foods. His attention span was short and therefore he would not remain sitting for a long enough period to finish his meal. During hospitalization his intake had ranged between 73-130 kcal/kg/day, with an average of 100 kcal/kg/day. This was sufficient to maintain, but not to promote weight gain. The child would eat when encouraged but would shortly attempt to get out of the chair to move about. The mother was at the hospital for all meal times. The dietitian met with the mother and discussed appropriate foods with her. Originally the mother provided the dietitian with a meal list which, if the child had been eating regularly, would have promoted weight gain. She later admitted that this had been his intake on one particular day.

Tests. Much of the child's testing had occurred on an outpatient basis and included: serum phosphates, creatinine, carotene, urinalysis, urine amino acids, serum metabolics, hydrogen peroxide haemolysis test, routine coagulation, TSH, T4, T3, urine and blood for metabolic screen, serum calcium, phosphates and alkaline phosphatase. While in hospital the following test were completed: bone age x-ray, chromosomal analysis for fragile X syndrome, alkaline phosphatase, a skull x-ray, calcium and metabolic screen, capillary gases, and a sweat chloride. All tests results were within normal limits.

Developmental assessment. This testing completed prior to admission demonstrated successes at the 24-30 month levels, below that of the child's age. His language and fine motor skills were delayed. The child was active and moving much of the time.

Psychosocial assessment. A social worker at the Child Protection Centre met with the mother both in her office and in the mother's home. Mother #4 at no time demonstrated concern about meeting with the social worker and initiated some of the contacts herself.

The Admission

This child was below the 5th percentile for weight and height at admission and between the 10th and 25th percentile for his head circumference. The child presented as wiry, thin, with shiny hair, and engaging smile. He would "parrot" phrases and questions asked of him. He initiated three word sentences and phrases. He sometimes required three to four promptings before he would respond to the questioner.

Although the mother noted that he rarely had the opportunity to play with other children, child #4 was gentle with the other children on the ward and in the playroom. He was observed hugging the child from the next room and finding and giving a toy to an infant who had dropped it. Even when 'tearing around' the play deck he was careful to never run into anyone. He would initially show hesitation with new personnel but quickly would accept help to 'drive a car' around the play area. All staff noted that mother #4 was appropriate in her interactions with the child except for the suggestion that perhaps she could be more structured and firm in her directions to him.

Both the father and the paternal grandmother visited while the child was in hospital. On the father's visit he woke the child from his afternoon nap although the researcher had suggested that the child was tired and required his sleep. The paternal grandmother stated that she wished to have the child live with her.

The financial constraints placed on the mother's purchasing power in regard to food were discussed with the mother and the dietitian. The welfare worker was approached about the availability of counselling services for those on limited budgets. Books and pamphlets on how to extend one's buying power were obtained. There are home economists available to counsel families on obtaining the best purchasing power for their money. Before a family is able to obtain an increase in food allowance a physician must first order the type of special diet required. A nutritionist then reviews the diet request and

decides whether there will be an increase in the budget. Over the week the child did not gain weight while in hospital.

Follow up Appointments

The physician at the Child Development Clinic recommended that the child attend a special needs day care which the social worker in that unit was able to facilitate within two weeks. The mother first visited the centre to ascertain whether she was satisfied with the placement. Once she had agreed an intake meeting was arranged immediately and within the two weeks child #4 was attending the day care.

There was structured and unstructured play time both indoors and outdoors, lunch time, and a nap time for all the children. All children were expected to return the items with which they were playing before taking out new items. Those children with special learning needs spent one-on-one structured time with their assigned worker. Parents received daily updates on the children and were expected to maintain efforts at home. Communication, as well as verbal, was through a book which the child took home each evening.

Concerns and expectations that the day care workers had for the children were related to the mother. The mother was encouraged to visit the day care to observe the methods used by the staff. The child responded if the workers were firm and set specific guidelines.

The researcher visited in the home twice and once with the mother at the Child Protection Centre, specifically in regard to the study. Ongoing telephone communication was also maintained. The social worker at CPC was contacted by the mother on several occasions. The suggestion that mother #4 be enrolled in the Parent Support Program that specifically provides parents with assistance and education regarding personal needs, met

with enthusiasm from her. Because of the waiting list, this program was not accessed until six months following referral, but the mother expressed that she was interested and very much wanted to participate.

Additional service involved with the child/family was a community services worker who supervised the special needs worker and needs assessment team. Following a developmental assessment all of these disciplines met to evaluate service delivery to date and ascertain any additional identified needs. The mother was aware of and involved in ongoing case planning throughout the process.

The child, although he gained weight, remained below the 5th percentile for both height and weight. The child's intake was monitored at day care and it was noted that he ate well with no change in the child. His speech had improved markedly, his fine and gross motor skills were refined, and he was socializing with other children. He was noted to have special aptitudes such as an ability to quickly put together puzzles that others his age found difficult. In contrast, he could not be interested in becoming toilet trained and continued to wear a diaper. The special needs worker and the mother communicated frequently to maintain consistency in caring for the child.

APPENDIX M

CASE STUDY #5

Aged 14 Months

Admission to Hospital

This child was admitted to hospital for investigation of her slow growth. The parents had brought the child to the emergency ward complaining that they were unable to get her to eat. The family physician had not, according to the parents, expressed any concern regarding the child's small stature and lack of growth. The paediatrician suggested that it was in the child's best interest to determine what was limiting her growth. He had seen the child at his office on two occasions following the visits to the emergency unit, prior to admission to hospital.

Referral to the researcher was made two days after admission to hospital. The physician and nursing staff were to approach the parents regarding inclusion in the study. Developmental testing had been scheduled for the 4th day following admission. Because the parents did not have a telephone and did not leave a message number, the staff were dependent on waiting for the parents to contact the ward for information. A note that the parents had been informed of the developmental testing was omitted from the child's chart. When the parents did not arrive at the scheduled time it was decided to proceed, only to have the parents arrive 3/4 of an hour late.

The researcher was introduced by the physician and an explanation of the study given. The parents were then asked to decide over the weekend whether they wished to participate. An appointment was made to meet with the parents on the following Monday, allowing them three to four days to consider the request. This child's admission to hospital extended over a three month period with discharge home for one three week session. Weight was monitored by the physician during that time and readmission was instituted when no further weight gain occurred. Both admissions were considered as one for the study.

Assessment

History

Medical history. The child was the second born to this mother, the first to these parents. Child #5 had weighed between the 10th and 25th percentiles at birth. Information obtained from the maternity unit indicated no complications at birth.

The child's weight had remained between the 5th and 10th percentiles until approximately 12 months of age when she dropped below the 5th percentile. The child had been breast fed according to the mother as often as 17 times a day up to that time. The child did not drink from a bottle and would not eat solid food.

The father received medical care for "nerve problems" and was on daily medication. The mother presented as an extremely thin young woman who stated that she had been fat once and did not want to be so again. She could not state how tall she was but the researcher estimated her at 162 centimetres and the mother stated she was under "100 pounds". The mother said she did have regular medical checkups and that she had "stomach problems". A medical history of the grandparents was not available.

Social history. Each parent had previously been married and each had a child by those unions; those children remaining with the former spouses. Child #5 was the first child from this union. This marital relationship had been marked by separations on a number of occasions; neither spouse being able or willing to relate the exact number of separations.

Both the paternal and maternal grandparents lived in the city and the parents associated with each. The paternal step-grandfather was seriously ill in hospital at the time of the child's admission.

There was a history of alcohol abuse by the father; the extent or period of time not documented. The mother stated the father had physically abused her on a number of

occasions. She claimed that she was going to give "...him one more chance and then I'm gone".

Dietary intake. When the child was first admitted to hospital her weight, height, and head circumference were well below the 5th percentiles. To achieve weight gain the dietitian determined intake would have to be in excess of 120 kcal/kg/day. During the first three week period the child's intake ranged from 46-141 kcal/kg/day. The high end being reached when the child was being tube fed during the night. When the child's intake dropped to the low of 46 per day it was decided to institute tube feedings to prevent severe dehydration and resultant complications. These feedings were continued for 12 days. Two days post tube feeding the child was discharged home. Intake averaged at 60 kcal/kg/day during the 1st week and 100 kcal/kg/day the 2nd and 3rd weeks. The child's fluid intake remained under 300 millilitres per day.

This child would tightly close her lips and refuse to allow a spoon or nipple to enter her mouth. Dietary and nursing staff attempted to introduce all possible foods to entice the child to eat. Of interest was the fact that the child was not noted to seek her mother's breast despite the history of being breast fed frequently.

Although there were requests from staff, the parents were present at only 3-4 meal times during this period. On those occasions it was noted that the mother would stop feeding the child as soon as she closed her mouth the first time. The mother stated to the researcher that her family told her that the child would eat when she was ready. She did not "want to make the child dislike food by forcing her to eat at all". Information regarding the detrimental effects of malnutrition was presented to both parents and they were able to discuss this with the researcher.

Nursing staff developed a procedure of cuddling the child while talking to her and feeding her. Initially this resulted in the child screaming and refusing to eat, after which

she settled and ate her meal. Nursing staff would tell the child what a good girl she was, talk about the food, congratulate her when she ate a mouthful, but would continue feeding her. By the end of the admission she would eat for the nursing staff and for the mother, if a nurse remained beside the mother to encourage them both.

Tests. To rule out physical causes for the FTT the following tests were conducted: head ultrasound, sweat chlorides, complete urinalysis and urine for bacteriology (twice), alkaline phosphatase, bone age x-ray, albumin, electrolytes, total carbon dioxide, BUN, complete blood count and differential, a metabolic screen, and chromosome testing. All test results were within normal limits.

Developmental assessment. This testing was conducted without the parents present as they had not arrived for the scheduled appointment. The child tested at below her age for fine and gross motor skills. The parents were able to provide information regarding the ages at which the child had achieved developmental milestones.

Psychosocial assessment. On the first admission there was no psychosocial assessment of the family and the home environment. Although the physician had promised the parents there would be no social work involvement, the family situation precipitated such concern the child welfare agency was consulted.

While the child continued to maintain poor intake the parents again separated. The mother did not visit for one week but the father arrived to see the child as late as 2300 hours. On two occasions it had been noted that he smelled of alcohol. This prompted apprehension that the unstable family situation might result in the child being removed from hospital before she was medically fit. A referral was made to Child and Family Services to determine what assistance could be provided the family. Five days later a worker called to inform the hospital staff that the assigned worker was attending court and would not be available until the following Monday; a time lag of 10 days.

When the worker did contact the hospital the parents had reconciled and were demanding the child be discharged from hospital. The social worker met with the parents the day following discharge from hospital. It was noted by a number of professionals that the father served as the spokesperson while the mother remained silent and passive.

The 1st Admission

The child was petite, thin, and had thin wispy blonde hair. She would put her head down, close her eyes, and not look at staff. She would however, allow anyone to pick her up and then would cuddle to them. The child made no effort to crawl but would sit in the hall waiting for someone to pick her up. Child #5's face was expressionless, except when screaming if anyone attempted to feed her, and she did not smile. When having a temper tantrum, she would kick and scream but shed no tears. This would end abruptly if the staff stopped trying to feed her.

When the mother was present she carried the child on her hip or pushed her in the stroller. Nursing staff consistently attempted to persuade the mother to encourage the child to crawl and or walk while holding her hand. Teaching regarding the developmental needs of the child was done by the nursing staff and the head nurse. This head nurse remained late 3-4 evenings to assist and guide the mother through the feedings.

Parental visits continued erratically, particularly following the separation and then a death in the family. The father always presented as affable and pleasant. Alternatively, the mother was withdrawn, reserved and often appeared sullen and angry. She smiled rarely and did not respond openly when approached by staff.

The child continued to be indiscriminate with those who wished to hold her. She began crawling, and began to walk while held by one hand. She attended the play room where she was encouraged to play with toys and to develop her fine motor skills. She ate

small amounts and remained at admission weight.

The 2nd Admission

On a follow up appointment, after missing the first two appointments, the child had not gained any weight and the paediatrician admitted the child to allow for more time to change the child's eating habits. The social worker had not visited the home after her initial contact. The child's activity level remained the same as at discharge with no deterioration in her skills. Eating habits had regressed to the point that the child screamed whenever food was introduced.

One week following the 2nd admission the professionals working with the family met to attempt to plan for long-term care for this child. At this time it was emphasized that a psychosocial assessment was the absolute priority because, until some conclusions had been reached about family functioning, it would be impossible to determine the most effective methods to help this child and family.

The severity of the child's condition was explained again by the paediatrician and the parents were told that discharge would be dependent on the child's ability to gain weight. Appointments were made with the Child Protection Centre social worker. The worker met with both parents once, with the mother alone once for an in-depth assessment, and with the father alone once. She saw the parents briefly on the ward on two occasions but they would not meet with her again.

The child was given a day pass to spend Christmas Day at home with the family. The day following the parents supposedly had an altercation on the ward, although no nursing staff witnessed the incident. The mother did not phone or visit over the next week. The head nurse had spoken with the parents about the need for regular and consistent attendance at hospital to provide the child with a routine that could be continued at home.

The next team meeting the Child and Family Services (C&FS) worker did not attend. The health care professionals involved persisted in their efforts to emphasize the severity of the child's deprivation and the need for a coordinated approach and plan of care. At the third team meeting the C&FS social worker recommended that, because the parents had reconciled again, a parent aide in the home four hours a day over at least one meal time would be an effective method of assisting the family. The little girl was also to attend a special needs day care each morning. The parent aide spent a week and half at the hospital getting acquainted with the child and family and with the established routines.

The parents told the researcher they intended to change physicians following discharge. This course of action was discouraged and the concern the physician demonstrated for the child was emphasized. The need to consult C&FS was presented to the parents from the perspective that the agency was able to access resources that would assist the family. The parents stated they were able to understand the value in such action. The parents stated they were afraid the C&FS worker had the power to take the child from them. Discussion was held about the need for the child welfare agency to have this power and the reasons such action could or would be taken. The potential negative long term effects of not intervening in the child's slow growth were again stressed.

At discharge from hospital the child remained below the 5th percentile for all three parameters. However, there was a slight positive curve, indicating a start to catchup growth. Child #5 was walking alone steady on her feet, attempting some words and smiling and responding to interactions from her caretakers.

Follow Up Appointments

The parent aide attended in the home each afternoon. In conjunction with child life personnel and nursing staff she had developed goals and objectives for the child. These she shared and revised with the parents.

The researcher went to the home two weeks after discharge of the child. The little girl was starting to show discriminate behaviour as she would no longer attach to a stranger; the development of stranger anxiety being a positive step indicating attachment to her caretakers. She continued to display a short attention span; but recognized a paint brush the parent aide had purchased and wanted to paint.

Follow up appointments at the doctor's office showed the child's weight remained constant, neither gaining nor loosing. The mother and child moved to a crisis centre when the father was physically abusive. The parent aide continued to meet with the mother and child at the centre. Following this the mother then went to live with her family. During that time the parent aide did not meet in the home but continued speaking with the mother and child. Hospital staff were informed that the maternal grandmother did not agree with the method of feeding the child and wanted the child to be allowed to eat as she chose.

At the time of writing, the mother had moved to her own apartment. The child had an appointment to see the paediatrician that week. The head nurse had contacted the C&FS social worker with her concerns regarding the child and had discussed them with the physician. The parent aide continued meeting with family and noted the developmental progress the child had made. Day care resources were found with the suggestion that long term assistance would be of the most benefit to the mother/child dyad.

The child had reached the 5th percentile for weight. She was babbling with "no" as her only distinguishable word. Her gross and fine motor skills were age appropriate. A reassessment at Child Development Clinic was scheduled for the following month. The

child was beginning to feed herself and appeared happy and active. The parent aide was to continue to meet with the mother once a week while the child was to attend the day care five days a week. The mother appeared more relaxed and had begun to gain weight as well.