

An Examination of Life-Style Factors That Influence Parental
Support of Oral-Motor/Feeding Skill Development
of the Child with Down's Syndrome

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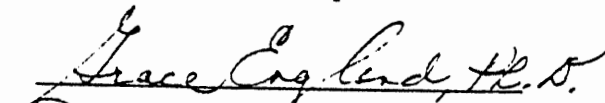
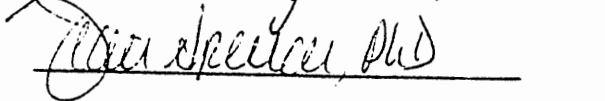
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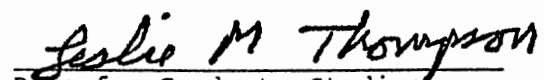
I am submitting herewith a thesis written by Geraldine L. Mueller, BS, entitled "An Examination of Life-Style Factors That Influence Parental Support of Oral-Motor/Feeding Skill Development of the Child with Down's Syndrome". I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree Master of Arts, with a major in Occupational Therapy.


Dr. V. White, Major Professor

We have read this thesis and
recommend its acceptance:

Accepted


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Abstract

An Examination of Life-Style Factors That Influence Parental Support of the Child with Down's Syndrome

Early intervention is a growing area of employment for occupational therapists. Inherent in the federal guidelines for programs is a family approach. Many occupational therapists in early intervention are involved in assisting families with determining the developmental level of oral-motor/feeding skills in their children with Down's Syndrome. It is the purpose of this paper to examine the parent(s)' perceptions concerning their child's oral motor/feeding skills and how recommendations for oral-motor/feeding skill acquisition were implemented in five families with different life-styles. Interviews were completed with the five families. As a complement to the interviews, a stress index was completed. Data were discussed in narrative for the interviews and the stress index. Results indicated that life-style factors influenced the care parents provided and, therefore, should be considered by occupational therapists when giving recommendations.

Geraldine L. Mueller, BS
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TABLE OF CONTENTS

ABSTRACT	iii
LIST OF TABLES	vi
Chapter I. Introduction.	1
Statement of the Problem.	2
Statement of the Purpose.	3
Background and Significance	3
Definition of Terms	4
Limitations	5
Basic Assumptions	5
Chapter II. Literature Review	6
Feeding	6
Feeding and the Down's Syndrome Child	7
Developmental Sequence of Oral-Motor Skills	10
Public Law 99-457	12
Families.	14
Occupational Therapy, Families, and Early Intervention.	16
Chapter III. METHODOLOGY	18
Research Method	18
Procedures for Collecting Data.	18
Procedures for Reporting Data	20
Subjects.	20
Chapter IV. RESULTS.	22
Interview Number One.	22
Interview Number Two.	25
Interview Number Three.	28
Interview Number Four	32
Interview Number Five	35
Results of the <u>Parenting Stress Index</u>	40
Chapter V. DISCUSSION	46
Implications for Occupational Therapists.	51

REFERENCES	54
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APPENDICES

A. Informed Consent Forms	58
B. Interview Format Guidelines	61
C. <u>Parenting Stress Index</u>	63
D. Graphs of <u>Parenting Stress Index</u>	70
E. Approval of Human Subjects Review Committee	76
F. Klein Independent School District Approval.	78
G. Reproduction Permission for <u>Parenting Stress Index</u>	80

LIST OF TABLES

Table 1 - Significant Findings of the <u>Parenting Stress Index</u> . . .	45
Table 2 - Summary of Families	47
Table 3 - Life-Style Factors Influencing the Acquisition of Oral-Motor/Feeding Skills	48

Chapter I. Introduction

Early intervention programs are growing rapidly in the United States due to the passage of the Education for the Handicapped Act Amendments of 1986, (Public Law 99-457), (Education of the Handicapped Act Amendments, Part H. [1986]). Part H of this law provided for the development and regulation of early intervention programs to serve the needs of developmentally delayed children ages birth to three years. The law emphasized a family focused approach (Dunst, Trevette, & Deal, 1988; Humphrey, 1989) which empowers or enables families to make their own decisions and in turn help to strengthen the family unit (Bazyk, 1989).

One large segment of the population served by early intervention programs includes children that are born with the diagnosis of Down's Syndrome. Due to congenital anomalies, these children may require the services of an occupational therapist in order to improve oral-motor/feeding skills. These children may have a short, narrow palate, underdevelopment of the maxilla, or a small oral cavity. They may be mouth breathers, or have generalized hypotonia of the facial muscles. These problems may result in poor lip closure, a weak suck, poor tongue control, and/or difficulty with jaw stability (Van Dyke, Peterson, & Hoffman, 1990). It has been documented that children with Down's Syndrome may have difficulty in early infancy with sucking and swallowing (Van Dyke, Peterson, & Hoffman, 1990). In young childhood,

drooling or persistent tongue protrusion may be a problem. Later, the child's transition from baby food to table food often presents problems.

In early intervention, occupational therapists are regarded as a primary service provider, allowing her or him to be a case manager and to work with the family in determining goals for the child. Due to the emphasis on empowering the family, collaborative goal setting must be done. The occupational therapist informs the family if she or he feels the child might have an oral-motor/feeding problem, but must not impose treatment on the family. Often families are dealing with other problems and are not willing to tackle a problem that they do not consider a high priority.

Statement of the Problem

The parent(s)' perceptions and the occupational therapist's perception of the oral-motor/feeding skills of the child with Down's Syndrome may vary greatly. The occupational therapist has a knowledge of oral-motor/feeding skill acquisition that most parents do not have. This obligates the occupational therapist to inform the parent(s) if the child appears to have an oral-motor/feeding problem. It is then the parent(s)' decision whether or not to treat the problem. The problem may be further complicated by differing life-styles and differing perceptions of whether or not the child has an oral-motor/feeding problem.

Often during the course of time spent in an early intervention program, priorities may change for the parent(s). One initial need often addressed is adjustment to the pain of not having a "normal" child. In order to serve as a case manager, the occupational therapist

must be aware of the current needs of the family and aware of the needs of the child. It is often difficult to balance the family's needs and the child's needs. It is intended through this research to identify the time at which the parent(s) perceive the need for an oral-motor/feeding assessment for their child with Down's Syndrome and to determine how parent(s) with five identified individual life-styles who were given oral-motor/feeding recommendations carried through with treatment.

Statement of the Purpose

This paper examined the parent(s)' perceptions of their child with Down's Syndrome concerning the child's oral-motor/feeding skills. The research also determined the influence of five individual life-styles on the ability of the parent(s) to carry out occupational therapy oral-motor/feeding treatment within the home setting. A third purpose was to identify parent(s)' needs and issues.

Background and Significance

Early intervention programs are growing rapidly, as are the numbers of occupational therapists employed in these programs. These therapists are providing services that range from case management to direct service to consultation. Very few studies have been done from the viewpoint of the parent(s)' perceptions. This research viewed the parent(s)' perspective of their child with Down's Syndrome oral-motor/feeding skills. Retrospectively, the researcher tried to determine when the parent(s) were more receptive to oral-motor/feeding assessment and intervention. This study examined the individual life-styles of the five families and how treatment recommendations were carried out by parent(s) within the different life-styles.

Definition of Terms

Down's Syndrome child. A child diagnosed as having Down's Syndrome and enrolled in an early intervention program or enrolled within the last year. The child will be between zero-and-three-years of age.

Life-style. Resources, events and situations impacting the family unit.

Parent(s). Parent(s) are defined as the primary caregiver(s) for the child or infant. Since a single parent family will be used for the study as well as the traditional two parent family, results will specify whether or not the child came from a two parent or single parent family.

Oral-motor/feeding skills. Oral-motor/feeding skills are those skills necessary for the child to ingest nutrients by mouth in order to sustain life.

Occupational therapist. An occupational therapist was defined as a graduate of an approved school of occupational therapy and certified by the American Occupational Therapy Certification Board to use the initial OTR (Occupational Therapist Registered).

Home setting. This is defined as the place of residence for the child and his or her parent(s).

Early intervention. Early intervention refers to a family focused program that was designed to meet the needs of developmentally delayed infants and children zero to three years of age. Early intervention programs follow the guidelines of the Education of the Handicapped Act Amendments of 1986, Part H (Education of the Handicapped Act Amendments. Part H [1986]).

Interview. This refers to a one to two hour session conducted by the occupational therapist with the parent(s) of a child with Down's Syndrome. It will take place in the home setting and be audio tape recorded.

Parenting Stress Index (PSI). (Abdin, 1986) The PSI is a diagnostic instrument used primarily with preschool children's parent(s). It assists the examiner with determining levels of stress in the parent's domain, the child's domain, and from outside environmental factors.

Limitations

This study is limited to the five different life-styles which are defined further in the paper. One other limitation was that the subjects were limited to the parent(s) of children with the diagnosis of Down's Syndrome that are between zero-and-three years of age and enrolled in an early intervention program or enrolled within an early intervention program during the last year.

Basic Assumptions

Basic assumptions were that many children with Down's Syndrome have oral-motor/feeding problems. It is further assumed that the study used only children that had some type of oral-motor/feeding problem.

Chapter II. Literature Review

Introduction

The literature review will discuss the development of oral-motor/feeding skill acquisition in the child with Down's syndrome as well as the normal sequence of acquiring oral-motor/feeding skills. It includes a historical perspective of early intervention and Public Law 99-457. A short section has been included on families. In conclusion, the literature review discussed occupational therapy's role with families in early intervention.

Feeding

Feeding provided a major component of daily living skills for infants and young children (Gorga, 1989). It provided a strong basis for the maternal-infant bonding process. The basis for growth and development was feeding. Without proper nutrition the energy needed for growth and development may be lacking. Studies have shown that children with developmental delays are prone to have nutritional deficits due to inadequate intake, poor utilization of the ingested food, or delays in the acquisition of oral motor skills (Brizee, Sophos & McLaughlin, 1980).

Feeding provided a multi-sensory activity of daily living in which all infants and children participate (Morris & Klein, 1987). The placement of the child stimulates the tactile system both to the body as a whole and to the oral structures (Montague, 1978). The auditory sense

was stimulated as the caregiver talks to the child. Visual skills developed during the feeding process due to the close body contact. Proprioceptive and vestibular stimulation were given during the handling and movement involved in feeding an infant. The feeding process itself stimulated olfactory and gustatory senses.

Oral-motor skills followed a definite sequence, as do other motor skills developed and refined over the first year of life. This sequence has been well documented by Morris and Klein, (1987). It paralleled the development of gross and fine motor skill development. Feeding started reflexively and progressed until voluntary, refined skills were acquired. Interruptions in this orderly sequence may be as mild as delayed speech on one end of a continuum to death from inadequate nutrition on the opposite end.

Feeding and the Child with Down's Syndrome

The literature concerning early intervention and the oral-motor/feeding skills of an infant or child with Down's Syndrome was limited. Harris (1980) described a transdisciplinary model for the treatment of infants and children with Down's Syndrome. She advocated the use of a developmental therapist. A developmental therapist was defined as an occupational or physical therapist with advanced training in the treatment of developmentally delayed infants and toddlers. This approach emphasized the use of parents as the primary teachers for their child. One of Harris's main goals was to provide oral-motor/feeding treatment in order to enhance independent feeding and prespeech activities.

Cullen, Cronk, Pueschel, Schnell, & Reed (1984) found that oral-motor/feeding problems in Down's Syndrome children were mentioned in only a few sources. Those sources reported difficulty with feeding, but did not study the development of feeding milestones for the infant or child with Down's Syndrome. Cullen et al. (1984) devised a study involving 114 newborn infants with the diagnosis of Down's Syndrome. The infants were studied for a period of three years from birth to age 36 months. At six-month intervals, the children were evaluated using the Vineland Social Maturity Scale. At the same time the parents were given specific suggestions to aid with the development of oral-motor/feeding skills. Results of this study suggested that the developmental sequence of feeding milestones was the same for a child with Down's Syndrome as a normal child, but the age that a child with Down's Syndrome developed specific oral-motor/feeding skills may be delayed. This delay may be as much as 35-percent for the infant with Down's Syndrome. Children with Down's Syndrome that had other congenital anomalies were even more delayed in the development of oral-motor/feeding skills.

In another study, a feeding questionnaire was given to 190 parents with a child diagnosed as having Down's Syndrome (Van Dyke, Peterson, & Hoffman, 1990). Almost one-half (49-percent) of the parents responded affirmatively when asked if their children had feeding problems. From this sample a subgroup of 58 children was studied. Ages ranged from one month to 19 years. Results of this study indicated that significantly fewer children with Down's Syndrome were breast fed. Forty-one percent of the children had a slight hypotonia of the oral region. The most

common concerns of the parents were: (a) difficulty with chewing, (b) poor lip closure, (c) choking and gagging while eating, and (d) a tongue thrust most often seen prior to the age of three. Overall, results of the study indicated that feeding problems were common in the young child with Down's Syndrome, but frequently resolved (in 60-percent of the cases) by early childhood.

Gissel, Lange, & Niman, (1984a, 1984b) studied tongue movements and chewing cycles in four and five year old children with Down's Syndrome. Twenty six children with Down's Syndrome were used for both studies. Results indicated that the child with Down's Syndrome received food with the tongue in a downward and outward position which is different from the normal child. Results of the chewing study revealed that the children often held the food in their mouths for a short period of time prior to chewing. Children with Down's syndrome cope with chewing difficulties by increasing the time spent in chewing.

Dobrofsky (1987) in a case study stated that muscular hypotonia contributed to weakness in tongue, lip, and jaw movements in children with Down's Syndrome. She treated a 30 month old child with Down's Syndrome five days per week over a six week period. Treatment consisted of desensitization of the oral regions, flattening, retraction, and lateralization of tongue movements, and activities to encourage jaw stability. Results indicated that following the six weeks of treatment, the child was keeping her tongue in her mouth 80 percent of the time, tactile defensiveness to the oral regions had decreased significantly, and the child was accepting new textures in food items with less resistance.

Developmental Sequence of Oral-Motor Skills

Alexander (1982), Morris & Klein (1987), Ottenbacher, Bundy, & Short (1983) have defined in great detail the developmental sequence of oral-motor skills. The following sequence has been adapted from Morris & Klein (1987). Oral-motor skills began in utero as space becomes cramped, and patterns of flexion developed. As space decreased in utero, the fetus developed a hand-to-mouth pattern and sucked on his or her fingers. At birth, a normal infant's feeding skills were reflexive. Sucking, swallowing, gagging, and rooting reflexes were present and aided the infant in locating and ingesting food. These reflexes provided protective measures for the infant. A true sucking pattern was present due to physiological flexion; however, it gradually diminishes as the infant began to develop mature motor patterns. Two to four ounces of fluid was ingested every three to four hours at birth by the infant.

By the age of one month, a predominantly suckling pattern was present. Motor control increased by three months of age while the initial reflex domination was becoming integrated and volitional patterns are developing. The sucking pattern has become one of suckling due to the loss of flexion patterns and emerging higher level reflexes. Caloric requirements have increased, and seven or eight ounces of liquid are taken at each feeding. If a spoon was presented to the three month old, he or she will attempt to suckle the food from it and may gag, choke, or cough.

By five months of age, the gag reflex was maturing so that by six months of age, most infants are ready for spoon feeding. They have

developed the necessary extension patterns to eat in an upright position. The suckle pattern was diminishing, and the tongue was developing an up and down movement pattern. Jaw and lip control increased. Oral reflexes, which had dominated feeding previously, are integrated. The baby was ready for soft, smooth solids. Initially the suckling pattern was used with the spoon, but infants quickly developed the jaw, mouth, and tongue control necessary to take food from a spoon. The six month old demonstrated interest in receiving liquids from a cup. This was a suck-suckle type of pattern and was poorly coordinated. Choking and coughing was to be expected as a protective measure.

The nine month old child has developed even greater fine and gross motor control. This control was manifested in improved oral-motor skills. The selection of foods had increased to include lumpy and smooth solids. The child was finger feeding some soft foods. Oral mouthing of objects between six and nine months of age has aided the transition to lumpy solid food and increased sensory awareness. The gag reflex had become increasingly normalized. Tongue movements were becoming lateralized and lip control increased. Chewing developed towards the sides of the mouth (lateralized). The nine month old becomes increasingly competent with a cup. He was able to take one to three sucks before stopping to swallow or breathe.

At approximately one year of age, the child was developing independence in feeding. The child was interested in self-feeding, and gets more food on her/himself and the chair than he ate. Diet consisted of coarsely chopped table food and easily chewed meats. Tongue laterality was used, and lip control had developed with the spoon.

Suckling patterns might still be present with a cup. Tongue control was developing. When biting hard food, earlier patterns might still be present due to the presence or absence of teeth. The child attempted to use a spoon to self feed.

The 15 month old child was refining oral-motor/feeding skills. Rotary type chewing movements were developing as the texture of foods becomes coarser. By this age, all table foods were appropriate. Less spillage occurred with a cup. The jaw had stabilized, freeing the tongue and lips for independent control. Choking and coughing happened infrequently as the child had normalized the gag reflex and developed the necessary oral-motor skills.

Public Law 99-457

Historically, Public Law 99-457, passed in 1986, initiated early intervention programs. This was an amendment to the Education of the Handicapped Act of 1986 (Education of the Handicapped Act, 1986). Part H encouraged early intervention programs. Part H also allowed occupational therapists to be regarded as primary service providers, and to provide case management services when necessary and appropriate. In order to receive federal funding, programs had to be in force by 1991. Purposes of the act included:

1. To enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay.
2. To reduce the educational costs to our society, including our nation's schools, by minimizing the needs for special

education and related services after handicapped infants and toddlers reach school age.

3. To minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society.

4. To enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps (Silverstein, 1989, p. 5).

In addition, Part H mandated family-centered services, interdisciplinary teams, and interagency collaboration.

Public Law 99-457 differed from Public Law 94-142 which provided for occupational therapy within public school systems (Silverstein, 1989). Public Law 94-142 provided related services for school children from ages 3 to 21, but services were offered on the basis of educational relevancy. This meant that in order to receive services, occupational therapy assisted the child within the educational setting. In contrast, Public Law 99-457 allowed the occupational therapist to be a primary provider and a case manager rather than a related service provider (Hanft, 1988).

The basic source of Public Law 99-457 came from Public Law 94-142, as Congress discovered studies showing that the earlier intervention was provided, the less was the dollar expenditure at a later time in the life of a handicapped child (Silverstein, 1989). Following this principle, Congress enacted landmark legislation so that states would receive incentives for serving all three to five year old children by school year 1991-92. This formed the basis for Public Law 99-457.

Congress also added Part H to the bill. Part H expanded the bill to provide services for zero to three year old infants and toddlers.

Families

Families have changed drastically within the last generation (Carter & McGoldrick, 1989). This was especially noticeable in the role of the mother. Many women now through choice, or economic necessity, maintained dual roles as mothers and family bread winners.

In addition to the dual roles of many mothers, families had become increasingly mobile in the last generation. This change often limited the family to immediate family members, rather than the extended family of generations past (Carter & McGoldrick, 1989). This in turn lead to the lack of an extended social support system in today's fast paced society.

In addition to the above changes, the definition of a "normal" family had also changed (Carter and McGoldrick, 1989). An ever increasing percentage of the population had chosen to live together without marrying. In the last decades the number of single parent families had increased dramatically, as did the number of families with step-parents.

In light of the above changes, the process of parenting was complex and influenced by many factors (Anderson & Hinojosa, 1984). Some of these factors were: (a) one's own past experiences with their parents, (b) the working through of feelings towards one's parents, and (c) one's values, traditions, and culture.

The essence of parenting lies in the exchange and feedback process between the parent(s) and child (Anderson & Hinojosa, 1984). This

parenting process was the same for a normal child as for the handicapped child; however, feelings of guilt, inadequacy, or anxiety may be intensified and prolonged for the parent(s) of a handicapped child. Critical to parenting was learning to deal with both the negative and positive aspects of full time care giving in the early years. Parent(s) of a disabled child may have difficulty with this aspect of parenting, secondary to delayed or abnormal developmental processes.

Hasselkus (1989) discussed the effects of care giving on the care giver and care receiver. In this case, the care receiver was the elderly, but the research could easily be duplicated using families with a child having Down's Syndrome. Hasselkus (1989) perceived of the care giver as a practitioner who was involved on a daily basis in a clinical reasoning process in order to maintain the health and well being of the care receiver. Therapists working with families must be aware of the daily reasoning process that care givers face in determining what was wrong, what can be done, and how it can be done. This was the same process used by an occupational therapist when presented with a new patient. Collaboration between the occupational therapist and the care giver (family) should minimize tension and assist in the decision making process.

In addition to the above, Hasselkus (1989) discussed the burden of care givers in terms of balancing care giving, with other of the individual's responsibilities, and the need for a work-leisure balance. Parent(s) with a child having Down's Syndrome faced many of the same dilemmas of care giving that Haselkus (1989) described. In addition, the family with a Down's Syndrome child was often younger in

chronological age; therefore, had less experience to call upon and use in order to face the problems of daily care giving.

Occupational Therapy, Families, and Early Intervention

Family-centered care and empowering the family were a high priority in the Handicapped Act Amendments of 1986 (Public Law 99-457). Early intervention programs emphasized the provision of occupational therapy services in collaboration with the child's family (Hanft, 1988). In order to develop these parent-professional relationships, the occupational therapist must have: (a) established a trusting relationship with the family members, (b) respected the family's traditions, values and beliefs, and (c) collaborated with the parent(s) in goal setting (Hanft, 1988).

Occupational therapists employed in early intervention are faced with many challenges. Services must be appropriate for both a medical and an educational setting while addressing the needs of the family (Stephens & Tauber, 1989). Another challenge was the need to case manage. This involved knowledge of available community resources, positive interaction with the family, facilitation of developmental skills in the child, and assisting the family with transitions, development of social networks, and problem solving (Case-Smith, 1989).

Occupational therapists are involved with the development of the Individual Family Service Plan (IFSP) for children enrolled in an early intervention program. The IFSP must be individualized for each child and address the needs of the family and the child within the family (American Occupational Therapy Association, 1989). The IFSP included: (a) a statement of the child's present level of development, (b) a

statement describing the family's needs and strengths in relation to the child, (c) expected outcomes from intervention, (d) what services are necessary in order to meet the child's and family's needs, (e) the date that services will begin and the duration of services, (f) the name of the case manager, and (g) the steps to be taken to aid the child in transition to preschool services if necessary (American Occupational Therapy Association, 1989).

In summary the literature review described feeding, feeding with the Down's Syndrome child, and the normal acquisition of oral-motor skills. The basis of early intervention program development was described. Changes within the family were researched and the role of occupational therapy with families and early intervention programs was discussed.

Chapter III. Methodology

Research Method

Ethnographic research was used to determine the effects of differing life-styles on the abilities of parent(s) to carry out oral-motor/feeding treatment within the home setting. Each family was involved in an early intervention program and had a child diagnosed with Down's Syndrome. Ethnographic research is designed to be qualitative in the data that is gathered so that it could be limited by interpreter bias.

Hasselkus (1989) used ethnographic research in order to study care giving for the elderly to assist occupational therapists in increasing their knowledge concerning the family and how to support the family unit. She used a series of ethnographic interviews with 15 family care givers of the elderly living within the community. The data gathered from the interviews was then transcribed and analyzed for themes and patterns. This research followed a similar format.

Procedures for Collecting Data

Prior to the interview, the researcher telephoned the participants, explained the research, and asked the parent(s) for a specific time to do the interview. The researcher, at the agreed upon time, went to the home of the participants, explained the research in detail, and the parent(s) signed the necessary consent forms (note Appendix A). A copy of the consent forms was left with the

participants. At this point data, gathering was begun through the use of the interview format guidelines (Appendix B). The interview was audio tape recorded. It varied in length from one to two hours. Following the interview the parent(s) were asked to complete the Parenting Stress Index (Abdin, 1983).

The Parenting Stress Index (PSI) (Abdin, 1983) was designed to be "an instrument whose primary value would be to identify parent-child systems which were under stress and at risk for the development of dysfunctional parenting behaviors or behavior problems in the child involved" (p. 39). The index was a diagnostic and screening technique designed to yield a measure of the magnitude of stress in the parent child system. It can be given to either the male or female parent. The rating scale contains 101 items assigned to two domains, the parent characteristics domain and the child characteristics domain. In addition, it contained an optional life stressors scale. Results yield an overall score as well as stress scores for the parent and child domains. Scores are considered significant for stress when percentiles are in the 0.90 range or above in any of the domains; 0.80-0.89 is borderline, and 0.10-0.79 is considered a normal stress level.

With ethnographic research, interviews can be structured or unstructured. This may depend on the skills or experience of the interviewer (Henerson, Morris, & Fitz-Gibbon, 1978). This interviewer used a variety of open-ended questions in order to elicit a depth of answers concerning the individual family life-styles and how oral-motor/feeding treatment was carried out. A direct approach was utilized as the interviewer explained that the purpose of the interview

was to gain information for occupational therapists concerning oral-motor/feeding skills of the child with Down's syndrome and to determine how treatment was carried out within varying life-styles so that the occupational therapist might have increased knowledge concerning family life-styles.

Procedures for Reporting Data

Data from the five audio taped interviews were transcribed. In addition, the Parenting Stress Index (Abdin, 1986) was computer scored. The data were then analyzed for consistent themes, or similarities and differences within the individual life-styles.

Subjects

Subjects were chosen according to the following guidelines: (a) each of the families were enrolled in an early intervention program or had been enrolled in an early intervention program within the last year, (b) each of the families had a child with the diagnosis of Down's Syndrome between the ages of zero to three years, and (c) each of the families represented one of five different life-styles. The life-styles were: (a) a traditional family life-style in which the father worked and the mother stayed at home (lower socioeconomic middle class), (b) a single parent family that had a significant other living with the family (middle socioeconomic class), (c) a single parent family without a significant other living within the family (lower socioeconomic class), (d) a family where both parents worked (middle socioeconomic class, and (e) a two parent family in which the Down's syndrome child had older siblings living at home (middle socioeconomic class).

At the completion of the interview, the researcher left the Parenting Stress Index (PSI) (Abdin, 1986) with the parent(s). A copy of this instrument is included in Appendix C. The PSI was used to determine consistencies between the interview data and the life-styles, and to determine patterns of similarities and differences among the five life-styles.

Chapter IV. Results

Introduction

Results of the five interviews will be discussed in detail in this section. In addition, results of the Parenting Stress Indexes (PSI's) (Abdin, 1986) will be discussed in this chapter. Appendix D includes graphs of the stress levels for each family.

Interview Number One

Interview number one was a traditional family life-style in which the father worked and the mother stayed at home. The family was of Spanish descent, and the Down's Syndrome child was three years of age. The family had an addition of a daughter who was nine months old at the time of the interview. Both parents were present for the interview, but the father chose to leave after the first few minutes.

In response to the question, "What factors influenced you to come to an early intervention program?" the mother answered, "We did not know how to work with the child. He could not sit up. At that time he just was not moving at all." He was seven weeks old.

The response to the question, "When did you perceive that your son had a feeding problem?" the mother stated, "Now I would say 'yes' (he had problems nursing), but then I would have said 'no.'" She then described the difference in nursing her son with Down's Syndrome and the new baby. She explained that at approximately seven weeks of age, she took him to a local hospital and a heart condition was diagnosed. She

stated, "At that time, he was so weak that he couldn't eat, he couldn't suck on me."

Prior to coming to an early intervention program, parent number one was given hints on feeding from the hospital where she had taken her son for the heart condition at age seven weeks. The mother stated she was told, "Exercise his mouth, position him in the upright position for the bottle, and try to stimulate him as much as I could with the nipple." Breast feeding was discontinued due to the process of counting calories in order to monitor intake, and he was started on an increased caloric formula. It was during this hospitalization that this mother heard of an early intervention program and subsequently enrolled her child.

In response to the question, "What information did you receive on feeding and from whom in the early intervention program?" the mother answered, "I received information from the registered occupational therapist." At approximately six months of age the Down's child received a formal consultation by the occupational therapist. The problems remembered were: "He wouldn't gain weight. He wasn't eating nothing and he was still having problems growing." The recommendations given at the consultation included sensory stimulation with a Nuk toothbrush and exercises to strengthen the lips and cheeks.

During regularly scheduled treatment sessions, this mother and child continued to receive feeding suggestions from the early intervention physical therapist as the occupational therapist was not present. In the mother's words, "I would ask her." These suggestions included the use of a tiny spoon and positioning for feeding. The

mother further stated, "It was with the occupational therapist that I worked mostly with the oral." She stated, "It was the occupational therapist who told me I do not have to follow a rigid feeding schedule and to feed the Down's child on demand." She also stated, "They discussed adding calories for increasing intake." Later she stated, "And the fact that we have always fed him at the table with us." was a recommendation made by the occupational therapist that had worked out well for their life-style. She felt that the recommendations were feasible for implementation at home and that they worked. In her words, "Yes, I think that they really did help me."

When asked what life-style factors had an influence on following the recommendations made for feeding, the traditional mother stated, "There wasn't anything. At that time, I guess you remember that I was totally dedicated to my child; all of me. The whole day I was dedicated to him only."

This mother felt that her child no longer had any feeding problems at the age of three years. She stated, "It is really a miracle from God." In response to the question, "Does your child require special attention?" the traditional mom answered, "Yes, well just his dressing, his diaper changing." The effect that this had on her life-style was that, "It takes a bit of time. It does slow me down as far as I am not able to just get up and go. We have to go through diapering them both." (She is talking about the child with Down's Syndrome and the baby sister.)

This child received a feeding consultation and information on oral-motor/feeding skills in the classroom. Both services were provided by the early intervention program's occupational therapist. Recommendations that were made for implementation within the family's life-style included, "The occupational therapist told me how to put the spoon in there and to press down, not to just stick it in and let it pour in (food) and to apply pressure to the tongue. And that is when she told me to, -- gosh I bet I still have that paper -- the different things to try with the child, like peanut butter toast and the different foods and putting it like over here to the side. I guess so that he would chew with the molars." In the classroom, recommendations included, "I know we have talked a lot in class, some of the stuff I can remember is transitioning from baby food to textured food. I remember telling her he had this big thing about applesauce, and she said to put chopped up graham crackers in it and adding textures on a really slow basis."

When this mother was questioned if she was able to carry out the recommendations for feeding, she stated, "Yes." Further discussion led to life-style factors, such as time that had an effect on following out the recommendations. At that time, the mother was working and she stated, "When we would pick him up and get home, the child wanted to eat right then, and most of the time we didn't have time to crush the graham crackers, and later that night I would be too tired to go in there and crush up a whole bag of graham crackers so I'd have some ready for the next day." The significant other in this mom's life at this time was her mother with whom she lived.

Other life-style factors that had an effect on this single parent with a significant other were the addition of the surrogate father. About this, the mother said, "I think it was more positive because when one of us became frustrated, then the other one could take over (feeding him)." She stated that the presence of her mother living with her at various times was also positive. "She had suggestions to try different foods on him, than me." Another life-style factor this mother quoted as positive was during the time she was working and the child had a babysitter. "That made a big difference because he would eat other things for her because he would see other kids eat them." At the present time this mother is staying at home and babysitting for other children. She felt that this, too, would have a positive effect on her child.

On the negative side of life-style factors, this mother felt that the fact that the child spent every other weekend with his father and his family was detrimental. "Well, I know that him going to his Dad's every other weekend is probably the worst thing for his feeding. They want to baby him. They don't want to introduce new foods."

At the present time, this mother described her son's feeding skills, "Well he is very demanding as far as him wanting to feed himself. He does not like any help at all. He still has problems with textures, but the other night we tried to get him to bite off the (chicken) breast and he did."

The question, "How do you feel about the assistance you received from early intervention?" was responded to with, "I just wish there could have been ten occupational therapists when we were with early

intervention to work with the child. She was the only one who knew anything about feeding."

Both the mother and the significant other responded to the questions, "Does your child with Down's Syndrome require special attention and what effect does this attention have on your life-style?" The significant other responded, "Most of the time when we are here he pretty much wants the attention every minute. And he will do things like get up on the table if he is on the chair. I mean that you have less personal time to yourself, but you know, you want to do it anyway. You feel like you have to do it, it is because you want to do it. And we do." The mother responded, "I mean until my child goes to bed at night the whole day, I mean the whole day, our whole day is his and then it is us. And that is how it is probably with any parent."

Interview Number Three

Interview number three was with a single parent family without a significant other living with the family. The subject was a single mother, and the child was three years and six-months old. He had been enrolled in an early intervention program since the age of one and one-half years. The transition to early childhood was expected to happen in the near future.

In response to the question, "What influenced you to come to an early intervention program?" the mother answered, "Basically, it became pretty obvious that I needed help. I had no earthly idea what I was dealing with." He was approximately one and one half years old at this time.

This mom described her labor and delivery as being "overwhelming".

In her words:

Well, they immediately--the way they made it sound, while the doctor was still holding him--he was not even going to give him to me. While the doctor was still holding him in his arms after he was born, I'm still on the table, he was telling me, "We need to hurry up and get this child to a heart monitor and all this other kind of stuff 'cause he has these holes and all." It went downhill from there because the next time I saw him, he was stuck with things, and wires stuck out from everywhere and they were calling a cardiologist specialist, pediatric heart doctor. Well after I went through eight hours of all these tests and everything, the doctor told me at the very end of it, "Well, bring him back when he is seventy." Well I began right after that--I am one of these people who is very cautious--like don't look a gift horse in the mouth. So I took my baby and just drew him right in and just hid out. As far as going to work or anything like that, you know, I began selling everything so I could stay home.

Further into the interview she stated:

It took me almost a year before I'd even take him in to get his shots. I didn't have any money. By this time I was considered an indigent person. I don't like that word, but that is basically what I was. I was without employment, without an income other than what I could sell, baby-sit, or

train a horse or give a riding lesson or something like that.

I never took him to a baby sitter because I just didn't trust anybody. Not because I hate people or because I have a problem with that. It is just that. Like I said, that I had been dealt a responsibility and I really took it.

This mother related that she discovered a feeding problem as she began to feed her child baby cereal. "He started throwing up the cereal and I kept watering it down and watering it down until finally, I just kept him on a liquid diet. It was projectile. It took forever for me to even begin to get him used to the strained foods. I kept watering it down."

At approximately one-and-one-half years of age, this child was enrolled in an early intervention program. She enrolled him because, "I thought it (her child's feeding or lack of feeding skills) was a lack of my mothering ability." She was constantly feeding him and he was continuing to have projectile vomiting. She stated, "I'm thinking to myself, I know how to do this, why can't I do this?" (feed her child without him vomiting).

It appeared that a formal feeding assessment was not done. The early intervention diagnostician and the physician spoke with this mother concerning feeding during assessment. She related, "I'm suggesting to them in order for me to be able to be comfortable with this program, I have to have enough confidence in the way I've been doing things." No recommendations on feeding to be followed through with at home were made to this mother. She described the lack of recommendation as follows, "No, they've said, the way they put it was

'Whatever is comfortable for you--as long as he is getting his nutrition.' Plus, whenever they did his assessment he was assessed at 14 months behind (delayed), that they considered even though he is this age (chronologically) and he should be able to eat this kind of food, because he is mentally delayed, the feeding is working with his progress developmentally."

Since no recommendations were given to this mother concerning feeding, input was not available concerning life-style factors which had an effect on feeding. In the interview she described the difficulty she was having feeding the child and that she was spending most of the day in feeding prior to coming to an early intervention program.

She described his feeding skills at the age of three years and six months as, "Oh, he's eating a little bit of everything now except popcorn, Doritos, and stuff like that." At another point in the interview she stated, "He still drinks formula and eats baby food to this day. He still doesn't feed himself. If you give him three or four pieces of stuff or a whole cookie, it all has to go in at once and he doesn't chew, swallow, chew, swallow. He puts it all in his mouth, he crunches it, and he tries to swallow. He winds up with it all packed in the top of his mouth."

The assistance received from the early intervention program was described, "These people, I have no complaints whatsoever. Everything I tell them to follow, no matter how trivial or how uppity it might seem, because I want it done my way, I tell them I don't want nothing to go wrong and this is the way it has to be done or else I'm not going to be comfortable with it. And it is no problem for them."

When asked if her child needed special assistance, the single parent answered, "Well, the fact that he still does not understand the possibility of dragging things down on him, falling on him (the coat rack), had required special attention." Another difficulty was teaching the concept of hot in relation to a space heater.

When asked what this special assistance needed by her child had done to her life-style, this mother stated, "I'm a person who used to -- if I decided I wanted to go to Fort Worth, I was gone. Well now with my child I don't take many chances."

Interview Number Four

Interview number four took place with a family in which both parents worked. The child had been enrolled in an early intervention program since he was seven weeks of age. He is now two and one-half-years of age. He has no siblings. Mother did the interview alone since the father was at work.

In response to the question, "What factors influenced you to come to an early intervention program?" this mother stated, "What made me start intervention was because I wanted the best possible options for my child that I could have. He was signed up three hours after he was born because of my sister, (sister's name), who worked for the school district (where the early intervention program is located). And (he) started the program at seven-weeks."

In response to the question, "When did you first perceive or did you perceive that he had any feeding problems?" her response was, "He has never had any feeding problems. He has a problem with certain foods, but I don't think it is a feeding problem, but a tactile problem."

He doesn't like certain meats and he won't eat things like chips or pretzels, but he'll eat cookies. And he spits a lot of meat out." Later in the interview, the mother stated there was some difficulty with breast feeding. She said, "The thing I got hung up on was that he was so small they kept telling me they wanted to have his food monitored. They wanted his intake, so what I did was as crazy as I am. I pumped and breast fed that child ten weeks. I was determined he would be breast fed. He would have breast milk until I went to work and until his immune system was built up. Night feedings, I got up, fed him a bottle and still pumped my breast every four hours."

"What information did you get on feeding from the early intervention program?" was answered as follows: "I got really what the occupational therapist helped me with. The Nuk toothbrush and working on his mouth because we had trouble with him getting his tongue out, and we tried different sorts of tactile things." This parent never received a formal feeding assessment, but received recommendations in the one hour class sessions. In addition to the occupational therapist at the early intervention program, this child received private occupational and physical therapy since early infancy.

The private occupational therapist provided feeding recommendations for this child. In the mother's words, "She started with cookies at an early age so that he would like the feel of hard food. Then we started finger foods, probably at seven or eight months, and then at nine months, she taught him how to drink from a straw, and then we started on using different utensils and just different food textures."

Mom stated that he did not have a formal assessment at the early intervention program for feeding, but that feeding recommendations had been informal during his regularly scheduled weekly class. Recommendations such as the use of a Nuk toothbrush and specific exercises to strengthen the oral muscles had been made and followed without difficulty in the home setting.

This mother described the differences between the private occupational therapist and the early intervention occupational therapist as follows: "The early intervention occupational therapist did more of the mouth therapy. She (the private occupational therapist) did more feeding."

When this mother was asked if she were able to carry out the recommendations made by the occupational therapists, she replied, "Yes." She felt that the most important life-style factor that influenced carrying out feeding suggestions was cooking. "I think the biggest thing is cooking. I hold the load because my husband works nights. I'm big on popping one of the meals into the microwave. That is one of the reasons he doesn't like meat like he should because I don't cook meals."

Other life-style factors mentioned by this mother related to the use of her sister as a baby-sitter and the fact that he had several older nephews as role models while at her sister's house. The mother described the extended family relationship as,

He loves her cooking; and my nephews, sure he copies
them

I am not thrilled with his feeding skills now because he
is having a tendency to dumping his bowl over. At first I

was thinking he was having trouble getting it out of his spoon, out of the bowl and I am real proud of the fact that he can feed himself. He is very independent and he likes to feed himself--nobody helps him. I thought he was having trouble getting the last bite out of the bowl, so he dumped it over and I think it has become a force of habit. He'll take a few bites out of the bowl and then it immediately goes over. Then he eats right out of the tray.

Assistance from the early intervention program was described as "great." Mom did not elaborate any further. When asked if her child required special attention, she answered:

I think the biggest special attention he has is to communicate. Because people do not understand how he communicates, he needs me to teach people what he is trying to tell them. Lots of people don't understand sign (language) or sign from a two year old. So I think I am overprotective because of that and because he gets colds easier - respiratory problems.

The reported effects on life-style were minimal. The working mother related, "I don't know any different. He is my only child, so I don't know any different. I don't know any other way of life. So it really has no effect."

Interview Number Five

Interview number five was a two parent family in which the child with Down's Syndrome had older siblings. In this case there are two older brothers, ages five years and eighteen years. Both parents work.

The child with Down's Syndrome is three and one half years old and had switched from an early intervention program to an early childhood preschool class a month prior to the interview. The mother answered the majority of the questions during the interview, but the father was present and, with prompting, added input.

The factors that influenced this family to come to an early intervention program in the mother's words were, "Well, having been in special education before, I already know that is what they (Down's Syndrome children) needed." (This mother had been a speech therapist prior to returning to school to attain a master's degree.)

Problems with feeding were first perceived at approximately one-year-of-age. Mother said:

She didn't have problems with the bottle, so it wasn't until she actually started on food, because she started actual baby food later than when I say "normal," comparing her to her five year old brother. The pediatrician was not concerned about getting her off the bottle at one year. Usually they say at one year to get them off the bottle, but the pediatrician said, "No, she doesn't have teeth; why get her off the bottle?" She didn't start getting teeth until she was a little over a year old.

This mother stated that she initially was not concerned with feeding due to a congenital heart condition that made nutrition important. Mother was aware that there was a possibility of feeding problems, and she stated, "Yes, I knew that everything would be delayed,

and, yes, I knew that they had much lower tone, and that we would have more problems with the tongue and chewing."

The information from the early intervention program was from the classroom teacher during the child's first few months of life. The mother related:

The first year the only type of information I really got on feeding was when the teacher would give me handouts. As far as the occupational therapist, which I should not be negative about, but you know how I am about that occupational therapist. Her thing was like she told me early on, even when the pediatrician was not concerned about the infa-feeder about telling me to get her off of it. "She should not be on the infa-feeder." What I told her was that maybe she should not be, but I don't have the time right now. I will wait till summer. I thought it (the infa-feeder) was a lot easier. I could continue getting dressed in the morning and she could still get her cereal. And at night I could cook supper while she was getting her baby food. And I figured it wasn't really hurting, you were still developing the muscles with the sucking. So, I didn't let it bother me. It bothered me right at first, and then after thinking about it, I did not let it bother me because I knew enough about it, but if I had been a mother that didn't know anything about it, I think I would have felt very guilty. Feeling that I was not putting enough into what my child should be getting. And so I just waited until

the summer to work on it, when I had the time. And then the next year we had a different occupational therapist and she said, "If it gives you some time to yourself, don't worry about it." And that was wonderful.

This child never received a formal feeding assessment, but the occupational therapist was present in the classroom on a weekly basis. Recommendations given in the classroom included: "Well, she gave me those little Nuk toothbrushes and the toothbrushes that are used in a nursing home (toothettes). We talked about the frenulum and different ways to keep the tongue in. When we started on the food, the baby food, she gave me some ideas about how to place the spoon into her mouth and whether to put it on the side, try to put some on the side and to get her to chew and rub her gums. She also gave suggestions for cup drinking in the classroom."

Recommendations given by the occupational therapist to implement at home are mentioned in the preceding paragraph. This mother stated, "Most of the stuff I just said, yes, especially with the spoon she finally learned to keep it in her mouth. And with the drinking." A recommendation not feasible in this life-style was to discontinue the infa-feeder.

Life-style factors which were important in this family included time as mentioned above. The fact that both parents worked limited time available to dress in the morning and cook supper at night and provide the children with daily care. Mother stated, "That is probably still an issue; that is probably still why I am doing a lot of the feeding of her rather than letting her do it herself. By the time I've cooked supper

and I'm trying to get her younger brother to eat and getting her to eat, if I wait for her to feed herself, it might be 8:00 p.m. before we go up for our bath."

Other factors that were mentioned were the presence of siblings. The mother stated,

She is still not real good at handling her own food. So I still sit and feed her, especially if I do not have time, if I need to go. Her brother then wants to be fed. He said it is not fair that sister gets to be fed. Then when the older brother was here, it helped out because a lot of time he could sit here and feed her while I was doing something else.

Mom stated, "I think she should be feeding herself. She wants to and she is at that stage now, she wants to." This was in response to the question, "How do you feel about her feeding skills now?"

In response to the question, "How do you feel about the assistance you received on feeding from the early intervention program?", this mother related:

The first half year I didn't like it too much, but afterwards, I don't know, I know I didn't need less, I might have needed more, but it was probably just as much my fault because any time I brought something up, the occupational therapist immediately worked on it. The classroom teacher was really good about incorporating it, and I guess sometimes with the feeding, because it is so important, not only because they need the food, but just socially too. Once they

go to school, they have to sit down and eat with other kids and the teacher doesn't have time to feed every single one of them. So, I don't know if that is something that maybe half the time needs to be devoted to that, but until they are ready for it; actually it depends on each child. She (her daughter) probably could not have stood half the time working on it (feeding), but probably 15 minutes each session.

The question, "Does your child with Down's Syndrome require special attention?" met with this answer:

Yes, I guess I think about my younger son at this age. He wouldn't get into something that he definitely shouldn't. You can't let her into a store, you can't leave her in a room too long by herself except in her bedroom without her getting into something she shouldn't. I guess another factor is like with baby-sitting. When you have a child like this, you don't want to leave them with just anybody, but it is a little harder when they are younger and all the feeding problems and things like that to find someone that is going to be responsible. Usually you get a teenager and by this age, they are feeding themselves and you don't really have to worry about it, but with her, you still do because she'll choke on something.

Results of the Parenting Stress Index

The traditional family's Parenting Stress Index (PSI) (Abdin, 1986) indicated high stress levels in the child domain. An overall stress score of 0.90% was obtained with a 0.95% in the child domain and

a 0.75 % in the parent domain. The stress appeared associated with difficult characteristics of the child (Abdin, 1983). In the child domain, the characteristics which were significant included: adaptability (behavioral characteristics which make him difficult to manage), acceptability (the child does not match the parent's hoped for child), demandingness (the child places significant demands on the parent for attention and assistance), mood (a general lack of positive affect), and parent reinforcement (the child is not particularly rewarding or reinforcing to the parent). In the parent domain, the significant stressor was the absence of a strong social support system. In addition, restriction of roles and parent health provided a moderate amount of stress for the parent.

In relation to the interview, the results of the PSI appeared accurate. The Down's Syndrome child was the first child of these parents. With the addition of another child, a comparison of development between the two children may well be indicators of the delays in development of the Down's Syndrome child. Time was mentioned by the mother as a life-style factor which was more difficult to find with the advent of two children in diapers so that a strong social system outside of the home may well be missed. The mother stated in the interview, "So it does slow me down as far as I am not able to just get up and go. We have to go through diapering them both." This situation may also relate to the mother's strong sense of isolation or absence of a social support system.

Interview number two was with a single parent living with a significant other. Results of this PSI indicated that the amount of

stress this family was feeling was within the normal range (overall score in 0.65% percentile, 0.85% in the child domain, 0.35% in the parent domain). In the child domain, it indicated that the child presents with a moderate degree of management problems and demands for attention and assistance. This was indicated in the interview by the significant other when he stated, "I mean you have less personal time to yourself, but you know you want to do it anyway." The mother also mentioned that the total day is devoted to her child and that they were attending a class that dealt with behavior management.

The PSI ratings or scores of parent number three indicated a high degree of stress in both the parent and child domains. Scores were in the 0.95% overall, with a 0.95% in the child domain, and 0.90% in the parent domain. This interview was the single parent without a significant other. In the child domain, significant factors included: adaptability (the child may appear to be a management problem), acceptability (the child does not match with the parent's expectations for him), demandingness (the child places a number of demands on the parent for attention), mood (the child may present with a general lack of affect), child distractibility (the child may be overactive or have difficulty attending), and parent reinforcement (the child is not highly reinforcing to the parent). When these characteristics were compared with the interview, one remembers the mother describing her child's birth, feeding difficulties, and the tremendous changes in life-style.

The parent domain showed mild to moderate symptoms of depression and guilt. This mother mentioned her guilt in the interview. The parent domain also indicated that the mother lacks a sense of competence

and may be overwhelmed by the demands of parenting. This was demonstrated in the interview as the mom stated, "I thought it was a lack of my mothering ability or my ability. It was terrible because I am thinking to myself - you won't believe the stuff that went through my head." She is describing the feeding process with her child. Another characteristic that showed up in the parent domain was the absence of a strong social system. This absence was validated in the interview when she talked about not leaving the house often and her fear of using baby-sitters.

Interview number four was with a two parent family. Both parents worked and there were no siblings. The PSI indicated that the overall level of stress was within normal limits both in the child domain (0.10%) and the parent domain (0.05%). Perhaps the parent's last sentence during the interview paraphrased it. She said, "I don't know any different. He is my only child, so I don't know any other way of life." This was in response to the question, "What effect does the special attention your child needs have on your life-style?"

Interview number five was with a two parent family. Both parents worked and there were two older siblings. Results on the PSI indicated a high level of total stress (0.90%). Stress was in the 0.80% in the child domain and 0.90% in the parent domain.

In the child's domain the areas of significance included: acceptability (the parent's expectations of the child are not consistent with the child), demandingness (the child's demands for assistance and attention are unusually high) and, child distractibility (the child appears more active than expected). These results are validated by the

interview when the mother described the special attention that her child needed especially in comparison to the five year old brother. In addition, the mother mentioned that the child's feeding skills were not appropriate, but that time limited her ability to allow the child to feed herself.

In the parent domain, a lack of competence or confidence with regard to child development and management was a stressor. Additionally, the lack of a strong social support system provided a high level of stress. Neither of these stressors was strongly supported in the parent interview.

Summary

The Parenting Stress Index (PSI) (Abdin, 1986) supported the interviews. Graphs of the individual families scores can be found in Appendix D and a chart of significant findings on page 45. The PSI assisted in determining the lack of a strong social system in the traditional family, the single parent family, and the family where both parents worked, and had siblings. It was interesting to note the same three life-styles resulted in significant stress levels. The same three families had significantly high scores in the child's domain for characteristics of acceptability of the child. This may be of particular interest to occupational therapists working with families as a signal for increased assistance to families in dealing with a child who does not meet the families "dream."

Table 1

Significant Findings of the Parenting Stress Index

Family	Results
Traditional family	Significant levels of stress in domain (0.95%)
Single parent with a significant other	Normal stress levels (overall score in the 0.65%)
Single parent without the presence of a significant other	Significant levels of stress in the parent (0.90%) and child (0.95%) domains
Both parents work (No siblings)	Normal stress levels (overall score in the 0.05%)
Both parents work (Two older siblings)	Significant levels of stress in the parent domain (0.90%); moderate stress in the child domain (0.80%)

Chapter V. Discussion

Results of this study indicated that there are several significant life-style factors that influenced the acquisition of oral-motor/feeding skills in the Down's Syndrome child. These included awareness of the occupational therapist of differing life-styles, the absence or presence of siblings, the absence or presence of time in relationship to the parents working, awareness by the parent(s) of the normal acquisition of oral-motor/feeding skills, and the presence of baby-sitters or other role models in the Down's Syndrome child's life. Other factors which had an effect were whether or not the mother breast fed, and the presence or absence of other congenital conditions such as heart defects. Heart defects added to the parent(s) concerns for maintaining adequate nutrition during the first year of life which led to increased stress levels. Another life-style factor was socioeconomic level which allowed the two parent family without siblings to employ private therapists. A low socioeconomic level conversely affected the single parents ability to pay for professional or other help with her child. Table 2 summarizes the features of the families which participated in this research. Table 3 summarizes the life-style factors which influenced parental support for the acquisition of oral-motor/feeding skills.

Time appeared to be the most significant life-style factor mentioned by all the families except the two parent family without

Table 2

Summary of Families

Interview	Life-Style	Siblings
Number One	Traditional family (father works, mother stays at home) Middle socioeconomic class	One younger sister
Number two	Single parent (with significant other living in the home) Middle socioeconomic class	No siblings
Number three	Single parent (without a significant other living in the home) Lower socioeconomic class	No siblings living in the home
Number four	Both parents work Middle socioeconomic class	No siblings
Number five	Both parents work Middle socioeconomic class	Two older siblings

Table 3

**Life-Style Factors Influencing the
Acquisition of Oral-Motor/Feeding Skills**

Life-Style	Factors
Traditional family (father works; mother stays at home) (one younger sister)	<ul style="list-style-type: none"> • The absence of siblings during the first two years led to increased time and stress spent in feeding • Presence of a heart condition led to nutritional concerns • Difficulty with breast feeding • Economic factors due to lifestyle • Lack of social support system
Single parent family with significant other (no siblings)	<ul style="list-style-type: none"> • Difficulty with breast feeding • Lack of time when the mother worked • Lack of leisure time due to the child's need for attention (care giver's burden) • The presence of the child's grandmother in the home • Use of a baby-sitter was a positive factor • Regression of feeding skills during regular visits to biological father
Single parent (no siblings)	<ul style="list-style-type: none"> • Excessive expenditure of time with her child in feeding • Trust that the early intervention program would follow her wishes • Difficulty with feeding led to this parent questioning her mothering abilities • Lack of social support system

(Table 3 Continued on Page 49)

Table 3 (Continued)

**Life-Style Factors Influencing the
Acquisition of Oral-Motor/Feeding Skills**

Life-Style	Factors
Both parents work (no siblings)	<ul style="list-style-type: none"> • Difficulty with breast feeding • Private therapists (OT and PT) (economic factors) • Need for a baby-sitter was a positive factor • Father worked evenings and weekends so not available for oral-motor/feeding skill acquisition
Both parents work (two older siblings)	<ul style="list-style-type: none"> • Presence of a heart condition • Perceived lack of time led to use of an infa-feeder • Presence of two older brothers • Lack of time for self-feeding skill acquisition • Baby-sitters (fear of choking) • Lack of social support system

siblings. In general, there was a lack of time due to increased responsibilities for the mothers who worked. This was especially noticeable in the last interview where the mother worked and there were other siblings.

Lack of time was mentioned by the traditional mother and the single parent without a significant other in terms of excessively prolonged feeding sessions. This appeared to increase their stress levels in terms of maintaining nutritional status. A lack of time was especially noticeable in the last interview where the mother worked and there were other siblings.

Another noticeable theme was the lack of a strong social support system for three of the five families. It was conceivable that these families may have had an imbalance in the work-leisure dyad as described by Kielhofner (1980) in his model of human occupation.

All of the families described the use of peers as role models for their child with Down's Syndrome as a positive life-style factor. The traditional family with the addition of a younger sister who was quickly obtaining the developmental levels of her Down's Syndrome brother had a role model. The mother felt that this helped to motivate the child with Down's Syndrome in acquiring skills. The single parent with a significant other described the positive effects of her son going to a baby-sitter where other children's eating habits were copied when she was working, and the positive effects on feeding when she stayed at home and babysat. She felt that her son would attempt to imitate the other children in terms of oral-motor/feeding skill acquisition. The single parent without a significant other described the positive effects of

other children enrolled in the early intervention program as role models for her son's development of oral-motor/feeding skills. The family with both parents working and no siblings had an extended family group that included role models for her son. The only negative effect of role modeling came from the sibling of the two parent working family with siblings. The five year old brother wanted to be fed as his sister was; however, the teen-aged brother would take over feeding for his mother on occasion.

In addition, the Parenting Stress Index (Abdin, 1986) was administered to the families. This index determined stress levels in the family and child domains, and assisted in determining life-style factors which may have affected the families' support of the acquisition of oral-motor/feeding skills. Results indicated that the traditional family, the single parent without a significant other, and the family in which both parents worked and there were siblings, experienced high levels of stress.

Implications for Occupational Therapy

Although sample size in this research was small, implications for occupational therapists were numerous. An awareness of life-styles is necessary when making recommendations to families in order to follow the early intervention guidelines of a family focused approach (Dunst, Trivette, & Deal, 1988). Lack of information concerning life-styles may result in increased stress for families as indicated by interview number five in the situation with the infa-feeder. Since results of the Parenting Stress Index (Abdin, 1986) indicated that the majority of these families are experiencing increased stress, the occupational

therapist should make her home recommendations with care and knowledge concerning the individual life-styles.

The majority of the information given to these families came from the early intervention occupational therapist and indicated several times when intervention appeared necessary. Although most of these children were not enrolled in an early intervention program while breast feeding, this time period seemed critical and a time of increased stress for the nursing mother. Another critical time period appeared when the child transitions from baby food to table food. This indicated a significant time to monitor feeding skills in the Down's Syndrome child. This monitoring process could be done within the early intervention program by the occupational therapist.

Another significant pattern that emerged was the apparent high levels of stress that these families continued to experience. Although the majority of the children with Down's Syndrome were in their third year of life (the youngest was 30 months old), stress levels remained high especially in the area of parental acceptance of their child. The loss of their dream of a "normal" child continued to be an issue for all but one of the families. Occupational therapists should be aware of this and assist families in dealing with acceptance issues, and stress within individual family life-styles.

A knowledge of the community resources available for respite care and a knowledge of other community resources such as the Association of Retarded Citizens would aid the occupational therapist in development of the Individual Family Service Plan (IFSP). This was a part of the

occupational therapist's role within an early intervention program as stated by Hanft (1988).

Another implication for occupational therapists was the lack of a strong social system in three of the five families. This may be indicative of an imbalance in the work-leisure dyad (Kielhofner, 1980). Although leisure skills were not identified in the interview format guidelines, it is an area where further research was indicated. One assumption from this research was that the lack of a strong social system in these families led to increased stress levels. Further research was needed in order to determine how this life-style factor affected families with children having Down's Syndrome.

Despite the limitations of a small sample size, this research provided important data for the occupational therapist. All of the children in the study had some type of oral-motor/feeding problems during their first three years of life. It indicated the need for occupational therapists to be familiar with oral-motor/feeding skill acquisition and inclusion of goals for oral-motor/feeding in the IFSP.

Early intervention provides new frontiers for occupational therapists. This research encourages further research into life-style factors that are within the role of the occupational therapist in early intervention, and it encourages occupational therapists to become increasingly aware of life-style factors which influence their choice of recommendations to families. Life-style factors should have an influence on all recommendations that the occupational therapist might make, in addition to the area of oral-motor/feeding skills.

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APPENDIX A

Informed Consent Forms

TEXAS WOMAN'S UNIVERSITY
CONSENT TO ACT AS A SUBJECT FOR RESEARCH AND INVESTIGATION

I hereby authorize Geraldine L. Mueller, OTR, a student at Texas Woman's University, to conduct an interview concerning my child's feeding skills. In addition, I will complete a written Parenting Stress Index. The purpose of the research study is to determine how life-style factors affect the ability of parent(s) to support the development of feeding skills. The interview and the completion of the Parenting Stress Index will take place in my home and take approximately one and one-half hours. These procedures have been explained to me in detail by Geraldine L. Mueller, OTR.

I understand that these procedures may involve possible risks and discomforts such as the risk of loss of confidentiality, discovering that my child needs further oral-motor/feeding treatment, or becoming aware of personal stresses (from the Parenting Stress Index). I understand that there are potential benefits from my participation in this study such as assisting professionals who work in early intervention programs to consider recommendations that are feasible within different life-styles. The study may assist those who work in early intervention programs in determining the need for specific skill treatment for Down's Syndrome children enrolled in the program. There are no direct benefits for me or for my child from study participation.

I understand that in the unlikely event of physical injury resulting from this research, the Texas Woman's University is not able to offer financial compensation nor to absorb the costs of medical treatment. However, first aid will be provided as necessary.

An offer to answer all of my questions regarding the study has been made. A description of the possible attendant discomforts and risks reasonably expected have been discussed with me. I understand that I may terminate my participation in the study at any time without intimidation or prejudice to me or change in services for which I may be eligible.

Confidentiality of records identifying the subjects will be maintained by not identifying the subjects on the audio-tape recording except by number, and by the researcher keeping the audio tapes in a secure place at home, and by using the data gathered only for educational or research purposes. This system (using numbers to identify participants in the study) will also be used when publishing the results of the study.

If I should have any questions concerning this research or my rights as a participant in this research, or in case of a research related injury, I may contact Geraldine L. Mueller, OTR at 363-3081 or 320-4378.

Father _____	Date _____
Mother _____	Date _____
Guardian _____	Date _____
Witness _____	Date _____

TEXAS WOMAN'S UNIVERSITY

We the undersigned, do hereby consent to the recording of our voices by Geraldine L. Mueller, OTR, acting on this date under authority of the Texas Woman's University. We understand that the material recorded today may be made available for educational, informational, and/or research purposes; and we do hereby consent to such use.

SIGNATURES OF PARTICIPANTS

Date

_____	_____
_____	_____
_____	_____

The above consent form was read, discussed, and signed in my presence.
In my opinion, the person signing said consent form did so freely with
full knowledge and understanding of its contents.

Authorized representative of the
Texas Woman's University

Date

APPENDIX B

Interview Format Guidelines

Interview Format Guidelines

Interview format guidelines will address the following questions, but are not limited to:

1. What factors influenced you to come to an early intervention program?
2. When did you first perceive that your child had a feeding problem?
3. Did you recognize that your child had a feeding problem prior to coming to an early intervention program? Will you tell me about it?
4. What information did you receive on feeding from the early intervention program?
5. Who gave you this information?
6. Did your child have a formal feeding assessment or a consultation and by whom?
7. Was feeding referred to during regularly scheduled treatment sessions and by whom?
8. What oral-motor/feeding recommendations were given for you to follow at home?
9. Were you able to carry out the recommendations concerning feeding in your home? Why or why not?
10. What life-style factors such as time, work, siblings, etc. had influence on carrying out feeding suggestion and how?
11. How do you feel about your child's feeding skills at the present time?
12. How do you feel about the assistance you received from the early intervention program for feeding your child?
13. Does your Down's Syndrome child require special attention?
14. If you feel he or she does require special attention, what effect does this have on your life-style?

APPENDIX C

Parenting Stress Index

PARENTING STRESS INDEX (PSI)

Administration Booklet

Richard R. Abidin
Institute of Clinical Psychology
University of Virginia

Directions:

In answering the following questions, please think about the child you are most concerned about.

The questions on the following pages ask you to mark an answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel. **YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.**

Please mark the degree to which you agree or disagree with the following statements by filling in the number which best matches how you feel. If you are not sure, please fill in #3.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

Example: 1 ② 3 4 5

I enjoy going to the movies. (If you sometimes enjoy going to the movies, you would fill in #2.)

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(804) 296-8211

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Pediatric Psychology Press
320 Terrell Rd. West
Charlottesville, Va. 22901

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

1. When my child wants something, my child usually keeps trying to get it.
2. My child is so active that it exhausts me.
3. My child appears disorganized and is easily distracted.
4. Compared to most, my child has more difficulty concentrating and paying attention.
5. My child will often stay occupied with a toy for more than 10 minutes.
6. My child wanders away much more than I expected.
7. My child is much more active than I expected.
8. My child squirms and kicks a great deal when being dressed or bathed.
9. My child can be easily distracted from wanting something.
10. My child rarely does things for me that make me feel good.
11. Most times I feel that my child likes me and wants to be close to me.
12. Sometimes I feel my child doesn't like me and doesn't want to be close to me.
13. My child smiles at me much less than I expected.
14. When I do things for my child I get the feeling that my efforts are not appreciated very much.
15. Which statement best describes your child?
 1. almost always likes to play with me,
 2. sometimes likes to play with me,
 4. usually doesn't like to play with me,
 5. almost never likes to play with me.
16. My child cries and fusses:
 1. much less than I had expected,
 2. less than I expected,
 3. about as much as I expected,
 4. much more than I expected,
 5. it seems almost constant.
17. My child seems to cry or fuss more often than most children.
18. When playing, my child doesn't often giggle or laugh.
19. My child generally wakes up in a bad mood.
20. I feel that my child is very moody and easily upset.
21. My child looks a little different than I expected and it bothers me at times.
22. In some areas my child seems to have forgotten past learnings and has gone back to doing things characteristic of younger children.

1	2	3	4	5
Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree

23. My child doesn't seem to learn as quickly as most children.
24. My child doesn't seem to smile as much as most children.
25. My child does a few things which bother me a great deal.
26. My child is not able to do as much as I expected.
27. My child does not like to be cuddled or touched very much.
28. When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.
29. Being a parent is harder than I thought it would be.
30. I feel capable and on top of things when I am caring for my child.
31. Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house.
32. My child reacts very strongly when something happens that my child doesn't like.
33. Leaving my child with a babysitter is usually a problem.
34. My child gets upset easily over the smallest thing.
35. My child easily notices and overreacts to loud sounds and bright lights.
36. My child's sleeping or eating schedule was much harder to establish than I expected.
37. My child usually avoids a new toy for a while before beginning to play with it.
38. It takes a long time and it is very hard for my child to get used to new things.
39. My child doesn't seem comfortable when meeting strangers.
40. When upset, my child is:
 1. easy to calm down,
 2. harder to calm down than I expected,
 4. very difficult to calm down,
 5. nothing I do helps to calm my child.
41. I have found that getting my child to do something or stop doing something is:
 1. much harder than I expected,
 2. somewhat harder than I expected,
 3. about as hard as I expected,
 4. somewhat easier than I expected,
 5. much easier than I expected.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

42. Think carefully and count the number of things which your child does that bothers you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please fill in the number which includes the number of things you counted.
1. 1-3
 2. 4-5
 3. 6-7
 4. 8-9
 5. 10+
43. When my child cries it usually lasts:
1. less than 2 minutes,
 2. 2-5 minutes,
 3. 5-10 minutes,
 4. 10-15 minutes,
 5. more than 15 minutes.
44. There are some things my child does that really bother me a lot.
45. My child has had more health problems than I expected.
46. As my child has grown older and become more independent, I find myself more worried that my child will get hurt or into trouble.
47. My child turned out to be more of a problem than I had expected.
48. My child seems to be much harder to care for than most.
49. My child is always hanging on me.
50. My child makes more demands on me than most children.
51. I can't make decisions without help.
52. I have had many more problems raising children than I expected.
53. I enjoy being a parent.
54. I feel that I am successful most of the time when I try to get my child to do or not do something.
55. Since I brought my last child home from the hospital, I find that I am not able to take care of this child as well as I thought I could. I need help.
56. I often have the feeling that I cannot handle things very well.
57. When I think about myself as a parent I believe:
1. I can handle anything that happens,
 2. I can handle most things pretty well,
 3. sometimes I have doubts, but find that I handle most things without any problems,
 4. I have some doubts about being able to handle things,
 5. I don't think I handle things very well at all.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

58. I feel that I am:

1. a very good parent,
2. a better than average parent,
3. an average parent,
4. a person who has some trouble being a parent,
5. not very good at being a parent.

59. What were the highest levels in school or college you and the child's father/mother have completed?

Mother:

1. 1-8th grade
2. 9-12th grade
3. Vocational or some college
4. College graduate
5. Graduate or professional school

60. Father:

1. 1-8th grade
2. 9-12th grade
3. Vocational or some college
4. College graduate
5. Graduate or professional school

61. How easy is it for you to understand what your child wants or needs?

1. very easy,
2. easy,
3. somewhat difficult,
4. it is very hard,
5. I usually can't figure out what the problem is.

62. It takes a long time for parents to develop close, warm feelings for their children.

63. I expected to have closer and warmer feelings for my child than I do and this bothers me.

64. Sometimes my child does things that bother me just to be mean.

65. When I was young, I never felt comfortable holding or taking care of children.

66. My child knows I am his or her parent and wants me more than other people.

67. The number of children that I have now is too many.

68. Most of my life is spent doing things for my child.

69. I find myself giving up more of my life to meet my children's needs than I ever expected.

70. I feel trapped by my responsibilities as a parent.

71. I often feel that my child's needs control my life.

72. Since having this child I have been unable to do new and different things.

1	2	3	4	5
Strongly	Agree	Not	Disagree	Strongly
Agree		Sure		Disagree

73. Since having a child I feel that I am almost never able to do things that I like to do.
74. It is hard to find a place in our home where I can go to be by myself.
75. When I think about the kind of parent I am, I often feel guilty or bad about myself.
76. I am unhappy with the last purchase of clothing I made for myself.
77. When my child misbehaves or fusses too much I feel responsible, as if I didn't do something right.
78. I feel everytime my child does something wrong it is really my fault.
79. I often feel guilty about the way I feel towards my child.
80. There are quite a few things that bother me about my life.
81. I felt sadder and more depressed than I expected after leaving the hospital with my baby.
82. I wind up feeling guilty when I get angry at my child and this bothers me.
83. After my child had been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected.
84. Since having my child, my spouse (male/female friend) has not given me as much help and support as I expected.
85. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend).
86. Since having a child my spouse (or male/female friend) and I don't do as many things together.
87. Since having my child, my spouse (or male/female friend) and I don't spend as much time together as a family as I had expected.
88. Since having my last child, I have had less interest in sex.
89. Having a child seems to have increased the number of problems we have with in-laws and relatives.
90. Having children has been much more expensive than I had expected.
91. I feel alone and without friends.
92. When I go to a party I usually expect not to enjoy myself.
93. I am not as interested in people as I used to be.
94. I often have the feeling that other people my own age don't particularly like my company.
95. When I run into a problem taking care of my children I have a lot of people to whom I can talk to get help or advice.

1
Strongly
Agree

2
Agree

3
Not
Sure

4
Disagree

5
Strongly
Disagree

96. Since having children I have a lot fewer chances to see my friends and to make new friends.
97. During the past six months I have been sicker than usual or have had more aches and pains than I normally do.
98. Physically, I feel good most of the time.
99. Having a child has caused changes in the way I sleep.
100. I don't enjoy things as I used to.
101. Since I've had my child:
1. I have been sick a great deal,
 2. I haven't felt as good,
 4. I haven't noticed any change in my health,
 5. I have been healthier.

STOP HERE — unless asked to do items below

During the last 12 months, have any of the following events occurred in your immediate family? Please check on the answer sheet any that have happened.

102. Divorce
103. Marital reconciliation
104. Marriage
105. Separation
106. Pregnancy
107. Other relative moved into household
108. Income increased substantially (20% or more)
109. Went deeply into debt
110. Moved to new location
111. Promotion at work
112. Income decreased substantially
113. Alcohol or drug problem
114. Death of close family friend
115. Began new job
116. Entered new school
117. Trouble with superiors at work
118. Trouble with teachers at school
119. Legal problems
120. Death of immediate family member

APPENDIX D

Graphed Results of the Parenting Stress Index

Case ID: 001
3-2-91

PARENTING STRESS INDEX
SCORE SUMMARY

	Parent's Scores		Raw Score Norms	
	Raw Score	Percentile*	\bar{x}	S.D.
TOTAL STRESS	274	90	221.1	38.9
CHILD DOMAIN	135	95	98.4	19.2
Adaptability	36	99	24.5	5.7
Acceptability	22	99	12.5	1.6
Demandingness	26	95	18.1	4.6
Mood	13	90	9.6	2.9
Discract/Hyper	25	60	24.4	5.0
Reinf. Par.	13	90	9.3	2.9
PARENT DOMAIN	139	75	122.7	24.6
Depression	16	20	20.4	5.6
Attachment	13	65	12.6	3.1
Restrict. Role	26	90	19.0	5.2
Sense of Comp.	33	75	29.2	6.3
Social Isolat.	18	90	12.8	3.8
Relat. Spouse	19	70	16.8	5.1
Parent Health	14	80	11.9	3.3
LIFE STRESS (Optional)	NOT ADMINISTERED		7.9	6.6

*10 - 79 Percentile: Normal Range
80 - 89 Percentile: Borderline
90 - 99+ Percentile: Clinically Significant

Case ID: 002
3-2-91

PARENTING STRESS INDEX
SCORE SUMMARY

	Parent's Scores		Raw Score Norms	
	Raw Score	Percentile*	\bar{x}	S.D.
TOTAL STRESS	231	65	221.1	38.9
CHILD DOMAIN	118	85	98.4	19.2
Adaptability	33	95	24.5	5.7
Acceptability	16	85	12.5	1.6
Demandingness	25	95	18.1	4.6
Mood	7	25	9.6	2.9
Discract/Hyper	30	85	24.4	5.0
Reinf. Par.	7	30	9.3	2.9
PARENT DOMAIN	113	35	122.7	24.6
Depression	22	70	20.4	5.6
Attachment	8	10	12.6	3.1
Restrict. Role	17	40	19.0	5.2
Sense of Comp.	27	40	29.2	6.3
Social Isolat.	13	60	12.8	3.8
Relat. Spouse	16	50	16.8	5.1
Parent Health	10	35	11.9	3.3
LIFE STRESS (Optional)	NOT ADMINISTERED		7.9	6.6

*10 - 79 Percentile: Normal Range
80 - 89 Percentile: Borderline
90 - 99+ Percentile: Clinically Significant

Case ID: 003
2-27-91n

PARENTING STRESS INDEX
SCORE SUMMARY

	Parent's Scores		Raw Score Norms	
	Raw Score	Percentile*	\bar{x}	S.D.
TOTAL STRESS	288	95	221.1	38.9
CHILD DOMAIN	130	95	98.4	19.2
Adaptability	31	90	24.5	5.7
Acceptability	22	99	12.5	1.6
Demandingness	23	85	18.1	4.6
Mood	11	75	9.6	2.9
Discract/Hyper	33	95	24.4	5.0
Reinf. Par.	10	65	9.3	2.9
PARENT DOMAIN	158	90	122.7	24.6
Depression	26	85	20.4	5.6
Attachment	14	75	12.6	3.1
Restrict. Role	26	90	19.0	5.2
Sense of Comp.	41	95	29.2	6.3
Social Isolat.	17	85	12.8	3.8
Relat. Spouse	21	80	16.8	5.1
Parent Health	13	75	11.9	3.3
LIFE STRESS (Optional)	NOT ADMINISTERED		7.9	6.6

*10 - 79 Percentile: Normal Range
80 - 89 Percentile: Borderline
90 - 99+ Percentile: Clinically Significant

Case ID: 004
2-23-91

PARENTING STRESS INDEX
SCORE SUMMARY

	Parent's Scores		Raw Score Norms	
	Raw Score	Percentile*	\bar{x}	S.D.
TOTAL STRESS	156	5	221.1	38.9
CHILD DOMAIN	73	10	98.4	19.2
Adaptability	16	5	24.5	5.7
Acceptability	10	30	12.5	1.6
Demandingness	11	5	18.1	4.6
Mood	5	5	9.6	2.9
Discract/Hyper	25	60	24.4	5.0
Reinf. Par.	6	15	9.3	2.9
PARENT DOMAIN	83	5	122.7	24.6
Depression	11	5	20.4	5.6
Attachment	10	25	12.6	3.1
Restrict. Role	9	1	19.0	5.2
Sense of Comp.	21	10	29.2	6.3
Social Isolat.	6	1	12.8	3.8
Relat. Spouse	9	5	16.8	5.1
Parent Health	17	90	11.9	3.3
LIFE STRESS (Optional)	NOT ADMINISTERED		7.9	6.6

*10 - 79 Percentile: Normal Range
80 - 89 Percentile: Borderline
90 - 99+ Percentile: Clinically Significant

Case ID: 005
2-23-91n

PARENTING STRESS INDEX
SCORE SUMMARY

	Parent's Scores		Raw Score Norms	
	Raw Score	Percentile*	\bar{x}	S.D.
TOTAL STRESS	271	90	221.1	38.9
CHILD DOMAIN	113	80	98.4	19.2
Adaptability	23	40	24.5	5.7
Acceptability	21	99	12.5	1.6
Demandingness	28	95	18.1	4.6
Mood	7	25	9.6	2.9
Discract/Hyper	27	75	24.4	5.0
Reinf. Par.	7	30	9.3	2.9
PARENT DOMAIN	158	90	122.7	24.6
Depression	29	95	20.4	5.6
Attachment	10	25	12.6	3.1
Restrict. Role	28	95	19.0	5.2
Sense of Comp.	35	85	29.2	6.3
Social Isolat.	16	80	12.8	3.8
Relat. Spouse	26	95	16.8	5.1
Parent Health	14	80	11.9	3.3
LIFE STRESS (Optional)	NOT ADMINISTERED		7.9	6.6

*10 - 79 Percentile: Normal Range
80 - 89 Percentile: Borderline
90 - 99+ Percentile: Clinically Significant

APPENDIX E

Approval of Human Subjects Review Committee

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON

HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER

HSRC APPROVAL FORM

Name of Investigator(s): Geraldine L. Mueller, OTR

Social Security Number(s): 459-86-9299

Name of Research Advisor(s): Virginia K. White, Ph.D., OTR

Address: 26314 Pine Canyon Drive
Woodlands, Texas 77380

Your study entitled: Early Intervention - Lifestyle Factors which
Influence the Acquisition of Oral-Motor/Feeding Skills in the Down's
(The applicant must complete the top portion of this form) Syndrome Child

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.

Any special provisions pertaining to your study are noted below:

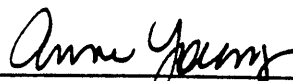
 Add to informed consent form: "I understand that the return of my questionnaire constitutes my informed consent to act as a subject in this research".

 The filing of signatures of subjects with the Human Subjects Review Committee is not required.

 Other: see attached sheet.

 No special provisions apply.

Sincerely,



Anne Young, Ed.D.
Chairperson, HSRC - Houston Center

2/19/91

Date

APPENDIX F

Klein Independent School District Approval

KLEIN INDEPENDENT SCHOOL DISTRICT

7200 Spring-Cypress Road • Klein, Texas 77379-3299

713/376-4180

DR. ROBERT LeBLANC
Assistant Superintendent
Instruction

March 19, 1991

To: Ms. Geraldine L. Mueller
Kuehnle Elementary School

From: Robert LeBlanc *RL*

Re: Research Request

Permission is given for you to conduct your study:

Early Intervention - Lifestyle Factors which Influence the
Acquisition of Oral-Motor/Feeding Skills in the Down's
Syndrome Child

As stated in the district research guidelines, a copy of the completed research
must be sent to me at the conclusion of the study.

RML:cjb

170

XC: Ms. Maryanna Richardson

APPENDIX G

Reproduction Permission for
Parenting Stress Index



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name of applicant <div style="text-align: center;">Geraldine L. Meller</div>		position or title <div style="text-align: center;">Registered Occupational Therapist</div>	
institution or organization and address 26314 Pine Canyon Drive Woodlands, Texas 77380			phone <div style="text-align: center;">(713) 363-3081</div>
highest degree <div style="text-align: center;">BS</div>	major <div style="text-align: center;">Occupational Therapy</div>	university <div style="text-align: center;">University of Texas</div>	year <div style="text-align: center;">1978</div>
List membership in professional organizations American Occupational Therapy Association, Texas CTA, Gulf Coast OT Association			

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<i>Test materials</i>	<i>Quantity</i>	<i>Describe use</i>
Test Booklet	6	Appendix in thesis

<p><small>If Research, please give Title and Brief Description of Project. (Use separate sheet if more space is needed.)</small></p> <p align="center">Early Intervention-Lifestyle Factors which Influence the Acquisition of Oral-Motor/ Feeding Skills in the Down's Syndrome Child.</p> <p align="center">A study involving the use of an interview format with the parents of 5 Down's Syndrome Children. The PSI will be use to assist with the validity of the interview.</p>
<p><small>Organization, Supervisor, or Person for whom work is to be done</small></p> <p align="center">Texas Woman's University Houston, Texas</p>

IMPORTANT NOTE

If you are a student, or if you are not a member of the American Psychological Association or similar professional organization, please have suprvising professor of psychology, of consulting or staff psychologist sign below your signature on page 2.

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11. Other:

applicant's signature	<i>Guadalupe L. Meyer</i>
signature of witness	<i>Steven W. Per</i>
signature of professor, consulting or staff psychologist, if required	

date	2-11-91
date	2-11-91
date	

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<i>Robert L. Abate</i>			2/15/91