University of Nebraska at Omaha
DigitalCommons@UNO

Student Work

8-1-1988

The Relationship of Actual Versus Needed Parent Participation and Stress Explained by Social Support

Ralf W. Schlosser
University of Nebraska at Omaha

Follow this and additional works at: https://digitalcommons.unomaha.edu/studentwork
Please take our feedback survey at: https://unomaha.az1.qualtrics.com/jfe/form/SV_8cchtFmpDyGfBLE

Recommended Citation

Schlosser, Ralf W., "The Relationship of Actual Versus Needed Parent Participation and Stress Explained by Social Support" (1988). *Student Work*. 1841.
https://digitalcommons.unomaha.edu/studentwork/1841

This Thesis is brought to you for free and open access by DigitalCommons@UNO. It has been accepted for inclusion in Student Work by an authorized administrator of DigitalCommons@UNO. For more information, please contact unodigitalcommons@unomaha.edu.

THE RELATIONSHIP OF ACTUAL VERSUS NEEDED PARENT PARTICIPATION AND STRESS EXPLAINED BY SOCIAL SUPPORT

A Thesis
Presented to the
Department of Special Education
and Communication Disorders
and the
Faculty of the Graduate College
University of Nebraska
at Omaha

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts: Mental Retardation
University of Nebraska at Omaha

by
Ralf W. Schlosser
August, 1988

UMI Number: EP73581

All rights reserved

INFORMATION TO ALL USERS
The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript
and there are missing pages, these will be noted. Also, if material had to be removed,
a note will indicate the deletion.

UMI EP73581

Published by ProQuest LLC (2015). Copyright in the Dissertation held by the Author.

Microform Edition © ProQuest LLC.
All rights reserved. This work is protected against
unauthorized copying under Title 17, United States Code

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 - 1346

THESIS ACCEPTANCE

Acceptance for the faculty of the Graduate College, University of Nebraska, in partial fulfillment of the requirements for the degree Master of Arts: Mental Retardation, University of Nebraska at Omaha.

Committee

Name	Department
Sharon Armfield	Special Education & Communication Disorders
Richard L. Wikoff	Psychology

Sandra K. Squires
Chairperson

August 22, 1988
Date

TABLE OF CONTENTS

PAGE

Acknowledgements.............................i

List of Tables. ii

Abstract...................................iii

CHAPTER

1 Introduction..............................2

Statement of Problem....................2

Review of Literature....................4

Hypotheses.............................43

2 Method...................................45

Population and Sample..................45

Instrumentation........................46

Procedures.............................51

3 Results..................................53

4 Interpretation of Results................66

Discussion.............................66

Limitations............................75

Conclusions............................76

Implications for Further Research.......76

BIBLIOGRAPHY...............................79

APPENDICES A. Demographic Data Sheet...............95

B. Questionnaire on Resources and Stress-Friedrich.....................98

C. Social Support Questionnaire Short-Revised..............................101
D. Parent/Family Involvement Index.....105
E. Letter of Invitation................110
F. Follow-Up Letter....................112
G. Table 11............................114
H. Table 12............................116
I. Table 13............................118
J. Table 14............................122

ACKNOWLEDGEMENTS

I want to thank Dr. Margaret P. Gessaman for selecting me as the recipient of the Fall, 1987 Rhoden Graduate Thesis Scholarship. I also want to thank the University Committee on Research for their financial support. I want to express my gratitude to Dr. Sandra K. Squires, Dr. Aaron Armfield, and Dr. Dick Wikoff for being, in the truest meaning of the word, teachers. I want to thank Dr. Paul Malcom for his kindness and assistance with the sampling procedure. I am indebted to Dr. Leon Rottmann and Ulrich Kapfer for their support in the recruitment of parents. I am grateful to Shoko Masuda for her love, empathy, and encouragement.

LIST OF TABLES

Table Page

1 Parents' Perceived Severity of Disability across Functional Areas........................51

2 Correlation Matrix: Parents' Perceived Severity of Disability related to Stress and Social Support..................................52

3 Multiple Regression Analysis on the QRSF Total Score and Four Factors...................55

4 Multiple Regression Analysis: Predicting Actual Parent Participation......................58

5 Multiple Regression Analysis: Predicting Needed Parent Participation.............................59

6 Comparison of Mean Scores Between Actual and Needed Parent Participation.....................61

7 Comparison of QRSF Mean Scores and Standard Deviations of Different Studies.................62

8 Social Support as a Predictor of Stress: R^2-Values...64

9 Comparison of Parent Participation Results with Cone's Study...................................66

10 Stress and Social Support as Predictors of of Actual and Needed Parent Participation: R^2-Values...68

11 Internal Consistency (KR-21) Values for the

Scale of the Parent/Family Involvement Index...114

12 Frequency/Percentage, Range and Mean of Demographic Information..........................116

13 Parental Perception of Severity of Disability: Functional Areas...............................118

14 Correlation Matrix: Concurrent Validity of the QRSF..122

ABSTRACT

This study examined the relationship of actual versus needed parent participation and stress explained by social support. It was the goal to develop a better understanding of individual differences in parents having a handicapped child related to actual and needed parent participation in their child's educational program.

The subjects were 100 parents of children across various handicapping conditions from 2 to 25 years of age (M = 11.1) in Omaha, Nebraska. Twenty-eight fathers and 72 mothers completed the questionnaires. The majority of respondents were married (80%).

The data collection procedures requested the completion of a "Demographic Data Sheet," the Social Support Questionnaire Short-Revised (Sarason, et al., in press), the Questionnaire on Resources and Stress-Friedrich (Friedrich et al., 1983).

Four hypotheses were stated: (1) parent's indication of availability of and satisfaction with social support will predict parental stress; (2) parental stress, availability of and satisfaction with social support will predict actual parent participation; (3) parental stress, availability of and satisfaction with social support will predict needed parent participation; (4) there will be a difference between actual and needed parent participation. A full model multiple regression analyses and a t-test were chosen to to test the hypotheses.

Results indicate that social support is a significant predictor of parental stress associated with having a handicapped child in a heretofore untested population (M = 11.1 years). Stress and social support neither predicted actual nor needed parent participation. A difference (22%) between actual participation and needed parent participation was found, providing empirical backup for unmet parent participation needs.

Results were discussed in terms of similarities and differences with other studies. Original assumptions were reconsidered in light of the new findings. Implications for further research were suggested.

THE RELATIONSHIP OF ACTUAL VERSUS NEEDED PARENT PARTICIPATION AND STRESS EXPLAINED BY SOCIAL SUPPORT

CHAPTER 1

Introduction

Research and discussion on parent participation in the children's educational program is moving toward individualization and a family systems perspective (Turnbull & Turnbull, 1982; Bowling Green State University, 1984; Winton, 1980; Vincent & Salisbury, 1988; Bailey, Simeonsson, Winton, Huntington, Comfort, & Isbell, 1986). Based on this deduction, it becomes important to understand differences among parents. The purpose of this study is to develop an improved understanding of individual differences among parents and their participation in educational programs of their handicapped children.

Statement of the Problem

The dynamic variables on which individual family preferences are based are not yet clear, and are only beginning to be researched. Parent stress associated with having a handicapped child and parental perceived availability of and satisfaction with social support are elaborated as potential variables to predict parent participation. A better insight in the relationship of actual versus needed parent participation, stress, and social support will contribute to the development of parent participation. On the basis of individual family needs and a family systems perspective beneficial effects of parent participation are procured and detrimental effects are avoided. The theoretical concept of a famlily systems perspective of Bronfenbrenner (1979) serves as a framework to comprehend the child as an integral part of an interdependent larger system with four ecological levels: a) microsystem; b) mesosystem; c) exosystem; d) macrosystem. The microsystem refers to patterns of activities, roles, and interpersonal relations experienced by the child in a given setting (e.g. home). The mesosystem involves interrelations among two or more settings in which the child actively participates (e.g. home-school relations). The exosystem refers to one or more settings that do not involve the child as an active participant but in which occurrences affect or are affected by the child (e.g. parent's social network). The macrosystems refers to consistencies such as lower-order systems (micro-, meso-, exosystem) that exist at the level of the subculture or culture (e.g. belief systems, ideology).

The explicit objectives of this study are stated as questions from the variables selected for consideration. The first question is directed at the relationship of stress and social support. The second and third questions pertain to the predictability of actual and needed participation when stress and social support are used as predictors. The fourth question compares reported actual and needed parent participation.

1) Is parental stress explained by social support?
2) Are parental stress and social support significant predictors of actual parent participation?
3) Are parental stress and social support significant predictors of needed parent participation?
4) Is there a difference in reported actual and needed parent participation?

In the following section, a review of literature most pertinent to the problems is provided.

Review of Literature

The literature on parent participation in the child's educational program, parent stress associated with having a handicapped child, and social support is reviewed. Parent participation is differentiated in two groupings: actual parent participation and needed parent participation.

Actual Parent Participation

For the purpose of this study, actual parent participation is defined as current involvement with the child's educational program in school, at home, and in the community. Participation areas in schools include classroom volunteering, observations at school, contact with the teacher, involvement in the special education process, and involvement in administration. Participation areas in the community are involvement in fund raising, advocacy, parent-parent contact and support, and disseminating information. Educational activities at home comprise the collection of data on child behavior, reinforcing and maintaining skills learned at school or suggested by the teacher, exchanging information with the teacher, etc.

Before reviewing concepts and studies on actual parent participation, the legal background of parent participation is described. The civil rights movement resulted in the enactment of the Education for All Handicapped Children Act of 1975 (PL 94-142). Congress perceived parent participation as helpful to handicapped children, their parents, and schools (Turnbull, & Turnbull, & Wheat, 1982). PL 94-142 has brought about changes in parent-school relationships and created new participation options for parent participation. This has involved decision-making, the Individualized Education Program (IEP), advocacy, case management, structured teaching, and program evaluation (Wolf, 1982; McAffee, & Vergason, 1979). PL 94-142 determines an active role for parents in IEP development: "1) parent participate in discussions about the child's needs for special education and related services, and 2) join with other participants in deciding what services, the agency will provide for the child" (Federal Register, 1981, p. 5468).

In 1987, PL 99-457 was passed by Congress to establish early intervention services for handicapped children under 5 years of age. The main theme of PL 99-457 and implications for this study will be discussed in the section on needed parent participation.

Actual Parent Participation in General. Shevin (1983) identified two models of current participation practices in terms of the extent to which parents are informed by teachers and the degree parents are involved in goal formulation: a) uninformed consent which is thought to be represented by the "acceptance of negative evidence," "presentation of best cues," and the "omission of alternative strategies" (ibid., 1983, pp 17); b) uninformed participation exists when parents are requested to identify long-term goals without regard to the parents' potential lack of information concerning appropriate goals (Shevin, 1983).

Several studies have investigated actual participation of parents of handicapped children in their children's educational programs. Cone, Delawyer, and Wolfe (1985) investigated parent participation of 229 families from five school districts and four states from the special educator's perspective. The greatest areas of involvement were found to be the contact with the teacher, and participation in the special education process. The least actual participation occurred in the classroom, involvement in advocacy groups, and disseminating information. By and large, teachers rated parents as mostly uninvolved. This study indicates that the mother's participation in educational activities at home was negatively related with the child's age, and the mother's involvement with administrators increased with older children. Mothers show increased participation in advocacy groups as their children's grade level increased. In 9 out of 12 involvement areas mothers scored higher than fathers. Although mothers and fathers respective levels differed, the pattern of involvment was similar for both. Participating in the special education process, contact with teachers, and transportation were the highest involvement areas for mothers and fathers. The lowest areas for mothers were classroom volunteering and participation in advocacy groups, and disseminating information. Fathers lowest areas were observation in school and involvement in advocacy groups. Cone, et al (1985) also found a highly significant positive correlation between the total involvement score and family income for mothers and fathers. The overall involvement score was again positively related with family income for mothers and fathers. The highest areas of participation for mothers denoting a relation with family income were "Educational Activities at Home" and "Involvement with Administration." The highest areas of participation for fathers revealing a positive relation with family income were "Involvement in Fund Raising Activities," and "Educational Activities at Home." Satisfaction with parent participation in a preschool program was positively related with family income (Posante-Loro, 1978). The total involvement score across 63 participation activities was found positively related with mothers' and fathers' educational levels. Also the overall involvement rating on a Likert-scale was a highly significant positive correlation with mothers' and fathers' education. "Educational Activities at Home" and "Involvement with Administration" were the highest areas of participation for mothers associated with the educational level. "Involvement in Fund Raising Activities" and "Educational Activities at Home" were the highest areas of involvement for fathers positively correlated with education. Along the same line, Meyer and Blacher (1987) identified mother's education level related to home-school communication ($r = .31$, $p < .05$). Etheridge, Collins and Coats (1980) assessed the attitudes of 104 low income, inntercity black parents toward their child's education. According to their study "parental willingness to become actively involved in and knowledgeable about their child's schooling is positively related to the educational level of parents" (ibid., 1980, p. 20). More precisely, respondents who completed eight years of schooling or high school perceived themselves as more actively participating in their child's schooling. In addition, parents with eight years or less of schooling were less inclined to serve as teacher aides or as volunteers in the child's classroom. Smaller families with 2-3 members were less inclined to participate in their child's educational program and to attend meetings to help their children in school.

A study by Lynch and Stein (1982) on perspectives of 400 parents, selected by eligibility for a free or reduced-cost lunch found that nearly one third of parents perceived themselves as not involved. Respondents who perceived themselves as participating elicited passive rather than active involvement. Differences in participation was not based on socioeconomic status. Parents of 13-14 year old handicapped students reported significantly less participation than parents of other age ranges.

So far, studies dealing with actual parent participation in the child's educational program in general have been reviewed. However, several studies have investigated actual parent participation specifically related to IEP meetings.

Actual Parent Participation in IEP Meetings. Salett and Henderson (1980) asked 2,500 parents of 46 states about their perceptions of participation. Fifty-two percent reported IEP's were completed prior to the meeting; 46% lacked information on how to appeal a contested IEP; and, 45% of parents felt that annual goals did not meet the child's needs. Yoshida, Fenton, Kaufman, and Maxwell (1978) requested a selection of potential parent activities during IEP-meetings from 1,372 professionals. Simply presenting information relevant to the case and gathering information relevant to the case were selected as the involvement by more than 50% of the parent respondents. Hoff, Fenton, Yoshida, and Kaufman (1978) found that 56% of parents had a minimal level of understanding of goals developed in the IEP meeting, and 50% of parents had a clear understanding of any of the four components of placement team decisions, including eligibility, placement, program goals, and review date. The actual parent participation in IEP meetings was perceived as low compared to professionals' contributions (Gilliam & Coleman, 1981). An observational analysis of 14 IEP meetings revealed that parents were primary recipients rather than speakers (Goldstein, Strickland, Turnbull, & Curry, 1980). In almost all cases, objectives and goals were not jointly developed between parents and professionals. In their analysis, Goldstein, et al. (1980) found that 12 out of 14 legally constituted meetings were attended by mothers and 3 by fathers. Conferences scheduled in the morning or early afternoon were discussed as obstacles for higher father attendance. Scalon, Aricks and Phelps (1981) examined the relationship of attendance to IEP meetings and the type of the child's handicap. Mothers of emotionally disturbed children were found as less participating (77 %) in IEP conferences than mothers of children with other handicapping conditions (99 %). Lynch and Stein (1982) found that parents of physically disabled students had less participation than parents with children with other disabilities. Becker, Bender, and Kawabe (1976) reported that parents of severely handicapped children were more keen on participating in their child's educational program than parents of less severely handicapped children. However, satisfaction with parent participation was found unrelated to the severity of disability in a preschool program (Posante-Loro, 1978). On the contrary, MacMillan and Turnbull (1983) suggest in their scholarly review that the severity of disability might result in parent burnout with school involvement possibly perceived as an additional burden leading to a preference not to be involved. Along the same line is the notion of LaCrosse (1982) that certain disabilities require a rather strict scheduling in order to make sure that all care giving demands can be met.

In summary, results of studies on actual parent participation are found to be not in accordance with the expectations of PL 94-142 related to parent participation in the child's educational program.

Needed Parent Participation

For the purpose of this study needed parent participation is indicated by parents' needs for participation in their child's education program in school, at home, and in the community. Potential participation areas and activities have been described earlier.

Research on parental needs for participation is scant. However, the evidence of low participation suggests that parental needs have not been met (Winton, 1986). Based on this evidence numerous authors proposed similar reevaluations of active and meaningful parent participation. The concepts of individualization and family systems perspective are reviewed as important factors in determining a comfortable level of parent participation.

Individualization. In their review of literature, Turnbull and Turnbull (1982) identified a dichotomy between PL 94-142 policies for children and for parents. While individualization for children is provided, it is lacking for parents, and families. Parents' rights for participation are becoming like "forces of imperatives" (Turnbull & Turnbull, 1982) in that parents of handicapped children feel guilty if they miss a school meeting. Schulz (1982), a parent of an exceptional child, states that professionals who emphasize active participation must realize that parents have individual needs and cannot be treated like a homogeneous group. This has been supported by an empirical evidence on parental involvement in which 19% of parents preferred the nonparticipation option at times. Informal contact was rated as the most preferable activity by parents. Overall, there were tremendous individual differences in parental preferences for participation activities (Winton & Turnbull, 1981). MacMillan & Turnbull (1983) disapproved of the assumption involved parents are good parents and uninvolved parents are bad. This position is an oversimplification because individual preferences are neglected and parents could be involved during the child's leisure time. An example of disregarding individual preferences is illustrated in the handbook "Individualizing Parent & Professional Partnerships:"

> Ms. Jones also works with Tom and Rhonda Clark concerning their son, Jason. Jason is a profoundly deaf two-year old child and is one of six siblings in a family situation often troubled by financial worries, serious illnesses and a limited social and emotional support system. The Clarks find that maintaining working hearing aids for Jason is an almost impossible task for them. The aids are frequently mislaid or damaged and dead batteries are the rule rather than the exception. Frequent

> upheavals in the home and the day-to-day care giving demands of the family leave Tom and Rhonda Clark feeling helpless regarding Jason's condition. They politely listen to Ms. Jones as she makes suggestions and demonstrates desired behaviors, but readily dismiss what she had to offer as soon as she leaves. (Bowling Green State University, 1984, p. 9)

Family Systems Perspective. In addition to the concept of individualization a family systems perspective is considered essential in planning meaningful parent participation (Winton, 1986; Bowling Green State University, 1984; Cieslewitz, 1985). PL 99-457 is based on a family systems perspective and will probably have a major impact on needed parent participation. It includes new concepts that were not required by earlier legislation, such as family involvement in early intervention based on a written Individualized Family Service Plan (IFSP), including multidisciplinary assessment of individual family needs and resources (Vincent & Salisbury, 1988). It is one intention of PL 99-457 to maintain that each family has available resources, both formal and informal, which can be used to meet its needs (Vincent & Salisbury, 1988). The focus on the family unit and not just the child with a disability is illustrated by a written policy statement of the Division for Early Childhood of the Council for Exceptional Children (1987):

> The family is the primary environment for the child. Services must support, not supplant, the family role; therefore family focused services are directed to the needs of the family; as well as the child. Since families represent the full range of the human condition, they require different kind of intervention services and different styles of service delivery.

Parent participation based on a family systems perspective has to be considered affecting the child, the parent-subsystem, the sibling-subsystem, interrelations of subsystems, and interrelations of subsystems with the community. Thus, a parent participation program with positive child outcomes might be counterproductive to other family members (Bowling Green State University, 1984). A participation program from a family systems perspective cannot be considered to be effective when negative parent outcomes (e.g. higher stress level) occurred even though the child outcomes were positive. Parental needs and the child's needs are not necessarily isomorphics, leading to conflicts of interests (Garbarino, 1982). For example, "parents need the child not to be in a special education program but the child needs specially designed instruction" (Turnbull & Turnbull, 1982). The following testimonial of a formerly active parent advocate provides some insight in potential detriments of parent participation in terms of parent outcomes:

> When he was first born we really got involved, and it was tremendously beneficial. But now I just want to draw back and make sure that this little guy gets it at home. When you're putting in so much time that your family is no longer benefiting from it, then it's time to quit and let somebody else do it...that's where we got. (Winton & Turnbull, 1981, p. 17).

Because of potential detriments of participation, MacMillan and Turnbull (1983) defend parents' rights for noninvolvment when they believe that this would be beneficial to the child and the family. This reasoning has been supported by a study of Winton and Turnbull (1981) in which 19% of parents preferred not to be involved at times. Allen and Hudd (1987) suggest, where parent involvement will benefit the child and the family, professionals need to provide an opportunity to do so; where not, professionals need to take action. To provide individually tailored parent participation options, the assessment of needs for participation and the assessment of individual differences among families is decisive (Bowling Green State University, 1984; Bailey et al., 1986). Parental input on the desired degree and type of involvement is perceived as an integral part of the assessment process (LaCrosse, 1982).

In summary, it is the goal to provide various types and degrees of parent participation that are matched to individual family needs and resources with benefits versus detriments as a measure.

Potential Predictors of Parent Participation

It is assumed that parental stress and social support determine individual differences among families and are therefore a decisive criteria in the effort for individualized and family-focused parent participation. This assumption will be addressed more extensively when stress and social support have been reviewed.

Stress. There have been various attempts to define the concept of stress. Rabkin and Streuning (1976) defined stress as an individual's response to events or changes that alter his or her social setting. Stress is occurring when "environmental and/or internal demands tax or exceed the individual's resources for managing them" (Holroyd & Lazarus, 1982, p. 22). For the purpose of this study, stress will be investigated as related to parenting an exceptional child according to the four factors examined by the Questionnaire on Resources and Stress-Friedrich (QRSF) (Friedrich, Greenberg, & Crnic, 1984): parent and family problems, pessimism, child characteristics, and physical incapacitation. Higher scores indicate greater stress. Mean scores from parents of nonhandicapped children are available from Dyson and Fewell (1986) and may be consulted (Table 7).

A body of research indicates that families with exceptional children are particularly vulnerable to stress (Gallagher et al., 1983; Farber, 1959; Holroyd & McArthur, 1976; Beckman, 1983; Friedrich & Friedrich, 1981; Wilton & Renaut, 1986; Dyson & Fewell, 1986). Wilton and Renaut (1986) compared stress levels of 84 New Zealand mothers of preschool intellectually handicapped and nonhandicapped preschool children (mean age/handicapped: 36.81 months; mean age/nonhandicapped: 35.34 months). Families with intellectually handicapped children reported significantly higher stress levels than the control group. Mothers' and fathers' educational levels failed to differentiate stress levels for parents of intellectually handicapped preschool children. Socioeconomic status did not appear to be a pertinent factor for differentiating stress levels.

Dyson and Fewell (1986) compared stress and adaptation in families of handicapped (mean age: 4.8 years) and nonhandicapped children (mean age: 4.7 years). A higher stress level was demonstrated by parents of handicapped children. The higher stress level was mainly defined by parental pessimism as a source of stress rather than additional caretaking demands and a restricted family and leisure life. Stress was found to be independent of the child's sex. Salisbury (1987) investigated stressors of parents of young handicapped (mean age/males: 2.7: mean age/female: 3.41) and nonhandicapped children (mean age/ female: 3.86). Rearing a young handicapped child was not perceived as more stressful than rearing a young nonhandicapped child. Salisbury (1987) assumed that age-related parenthood concerns rather than the handicap account for the stress level in families with young handicapped children. This assumption has been supported by Waisbren (1980) who found that parents of developmentally disabled children (mean age: 13.5 months) were similar to a nonhandicapped control group on most dimensions related to coping with a newborn baby in the first 18 months. Holroyd, Brown, Wikler, and Simmons (1975) identified age-related differences within a sample of parents with handicapped children. A higher stress level was found in families with older autistic children. Children ranged from 1 to 18 years (mean age: 10.5 years); the split was made at 9.5 years to divide the sample into young and old children.

Other studies focused on parent's sex as a factor of difference in parental stress related to having a handicapped child. Cummings (1976) researched the impact of the child's handicap on 60 fathers. Fathers of older children (9 to 13 years) showed slightly lower psychological stress than fathers of younger children (4 to 8 years). However, no significant relationship between the child's sex and stress was found. When comparing these results with an earlier study on mothers, Cummings concluded that mothers of mentally retarded children reported lower self-esteem and interpersonal satisfaction than fathers. Fathers of mentally retarded children had more difficulty in handling anger with the child. Fathers of chronically ill children seemed to recognize their psychic pain more readily. They also experienced a clearly reduced sense of competence as parents in contrast to mothers in the study.

Other dimensions of stress involved in rearing a handicapped child are the child-specific characteristics. Crnic et al. (1983) suggest that child-specific characteristics such as the severity of disability should serve as marker variables. Beckman (1983) investigated the influence of selected child characteristics on stress in 31 families of handicapped infants with a range from 6.6 to 36.6 months (mean age 21.6 months). Four selected child characteristics (temperament, responsiveness, repetitive behavioral patterns, and caregiving demands) were significantly related to stress reported on the QRS. The intercorrelation among the four characteristics suggests a "general difficulty of care." These results clearly indicate that the concept of severity is better illustrated by underlying child characteristics such as caregiving demands and behavioral patterns rather than superficial labels such as mentally retarded. For that reason, the author of this study preferred to gather scores on functional impairments across a variety of categories. No significant relationship was found between the child's age and the child's sex with the amount of stress. Stress associated with the severity of handicap was higher for parents of institutionalized children than for parents of noninstitutionalized children (Holroyd, et al., 1975). Mothers of autistic children reported more stress than mothers of Down's Syndrome children (Holroyd & McArthur, 1976).

Holroyd and Guthrie (1979) examined stress related to 18 children with neuromuscular disease. The more advanced the disease, the more stress is placed on the primary caregiver.

Friedrich, Wilturner, and Cohen (1985) studied coping resources and parenting with a sample of mentally retarded children with no motoric or sensory handicaps (N = 49), mentally retarded children with accompanying cerebral palsy (N = 41), and children with Down's Syndrome (N = 30). The severity of disability was found to be significantly related to QRSF factor "Parent and Family Problems." In a follow-up study, 10 months later, there was a significant increase in depression as measured by the Beck Depression Inventory of mothers with older children.

McKinney and Peterson (1987) examined predictors of stress with 67 mothers of developmentally disabled children. Increased stressor scores were obtained for increasing severity of physical disability, especially related to child demandingness and child mood.

In addition to child characteristics, the review of literature suggests that transition over the life cycle of handicapped children is related to parental stress (Friedrich, et al., 1985; Wikler, Wasow, & Hatfield, 1981; Wikler, 1986). The theories of chronic sorrow and periodicity are helpful to comprehend the concept of transition over the life cycle. The theory of chronic sorrow states that parents are repeatedly reminded about having a handicapped child when the child is in a transition stage of life (e.g. seeking for employment). This theory implies that a complete adjustment is unlikely to occur. The theory of time-bound adjustment proposes a contradictory concept. Parents go through a grieving process with the terminal stage of adjustment (Wikler, Wasow, & Hatfield, 1981). The periodicity theory assumes that "certain periods in the life cycle of a family with a retarded child may be associated with more manifest distress than are other periods" (Wikler, 1986, p. 703).

Wikler, Wasow, and Hatfield (1981) examined the adjustment process of 32 parents of mentally retarded children. Parental stress was measured at 10 newly introduced transition stages typical in the life cycle of a mentally retarded child and its family. Results indicate that parents experience chronic sorrow rather than time-bound adjustment. A comparison of the parents' and social workers' perceptions of the adjustment process revealed that social workers tended to overestimate how stressful the parents' early experiences were, and to underestimate how stressful later experiences were (e.g. 21st birthday). Wikler (1986) substantiated the periodicity theory in a study on periodic stress of families with mentally retarded children. A sample of 60 mothers of retarded children was sorted by chronological age in five groups: a) latency (7 to 10 years); b) onset of adolescence (11 to 15); c) middle adolescence (16 to 19); d) onset of adulthood (20 to 21); e) early adulthood (22 to 25). The onset of adolescence and the onset of adulthood are considered as socially designated stages and developmental milestones as well. Family stress was measured at two times (Year 1 and Year 3). Results indicate that family stress scores related to having a handicapped child were significantly higher at both times for transition families than for nontransition families. Along a similar vein, Bernheimer, Young, and Winton (1983) concluded from their research that heightened stress occurred at the following three times: a) time of initial diagnosis; b) the point at which help is first sought; and, c) the transition from an infant to a preschool program.

Another dimension of stress in families with a handicapped child is the family status. The composition of family units in the U.S. has undergone dramatic changes: single-parent families are increasing due to divorce and increasing births to single mothers (Rawlings, 1980). There is also going to be an increasing prevalence of single-parent families with handicapped children (US. Bureau of the Census, 1984). Weinraub and Wolf (1983) compared 14 single with 14 married mothers of nonhandicapped children. Increased emotional, social, and financial stressors were proposed as an indirect effect of father absence. Single mothers tended to face more stressful life events than their married counterparts. Investigating stress levels of 33 single mothers and 48 married mothers of handicapped children, Schilling, Kirkham, Snow and Schinke (1980) found differences only on one item of the QRSF: "I have given up things I really wanted to do in order to care for ...". The infinitely small discrepancy of single and married mothers is discussed as being partially attributable to the limitation of the QRSF as a true-false instrument.

In summary, research indicated that families of handicapped children face more stress than families with nonhandicapped children. Stress levels within families with a handicapped child are different as determind by the child's age, severity of disability, and family status.

Social Support. Social support is defined as the "existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us" (Sarason, Levine, Basham, & Sarason, 1983, p. 127); it has been used in vogue with the term social network (Sarason, Sarason, Hacker, and Basham, 1985). Social support is considered to have a number of dimensions, such as instrumental assistance, information provision, emotional empathy and understanding (Cohen & Wills, 1985; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Dunst, Trivette, & Cross, 1986; Thoits, 1986). Instrumental assistance is the provision of financial aid, material resources, and needed services (Cohen & Wills, 1985). Information provision refers to "...communication of opinion or fact relevant to current difficulties, such as advice, personal feedback, and information that might make an individual's life circumstances easier" (Thoits, 1986, p. 417). Emotional empathy involves demonstrations of love, caring, esteem, sympathy, and group belonging (Thoits, 1986).

Furthermore, social support may operate on various ecological levels as introduced by Bronfenbrenner (1979) such as support from spouse, friends, relatives, professionals, and parents of other handicapped children

(Gallagher et al., 1983; Segal, 1985). Also, social support has been considered as coping assistance, supplementing and strengthening an individual's effort of stress-management by guiding participation of significant others (Thoits, 1986). Regardless of how social support is conceptualized, there seem to be two (2) prevalent elements: (a) the number of available others to whom one can turn in times of need; and, (b) the degree of satisfaction with the available support (Sarason et al., 1983; Sarason, Sarason, Potter, & Antoni, 1985).

In the following, studies on various dimensions of social support such as the child's age and family income are reviewed as they are related to the utilization of social support over the life cycle of handicapped children. Suelzle and Keenan (1981) recognized changes in family social support networks over the life cycle of mentally retarded children. The utilization of personal social support networks decreased with increasing age of the child in contrast to utilization of professional support from health-care and school. Parents of younger as compared to older mentally retarded children contacted personal social support networks such as other parents of retarded children, family members and friends. Parents of older children were more inclined to perceive neighbors as less likely to accept their children in age-appropriate roles; thus, they perceived them as being less supportive. A u-shaped form in terms of family support, unmet service needs for crisis lines, respite care, and counseling services was identified which can be considered as an indication of satisfaction with social support. While unmet needs for support were high among parents of pre-schoolers, they dropped off for parents of elementary-aged children and teenagers, and increased again for parents of young adults. A difference in utilization of professional support was found depending on family income. While higher income families were less likely to have contacted family doctors, they were more likely to have contacted dentists. The highest unsatisfactory service needs were reported from parents of elementary-aged children and young adults, periods of transitional crises. According to Sarason, et al. (1986) social support was quite stable over time despite the fact, that college sophomore students are in a transition stage of life. The number of social support available was more stable than satisfaction with social support.

Crnic, et al. (1984) investigated effects of stress and social support on mother-infant interaction of mothers and nonhandicapped children from birth to 18 months. Mothers on public assistance reported less intimate support when their child was both one and eight months old. However, there was no association between family income and community support. Maternal education was unrelated to intimate as well as community support. Family status significantly influenced intimate support, with single mothers reporting less intimate support than their counterparts. There was no correlation between family status and community support identified. According to Weinraub and Wolf (1983) single mothers tended to encounter more isolation, were less consistent in social contacts, were less involved in organizations of parenting groups, and were less emotionally supported in their parenting role.

Several studies examined respite care as a special dimension of social support. Respite care is acknowledged for providing temporary relief from caregiving responsibilities to families of developmentally disabled and dependent persons living at home (Upshur, 1982; Salisbury, 1986; Blacher & Prado, 1986). In a study on respite care and service models for mentally retarded and other disabled populations, Upshur (1982) found that the actual provision of respite care is related to the severity of disability, with respite care most often furnished to mentally retarded and least often for autistic children and others with severe behavioral problems. Meyer (1986) identified severity of disability as a significant predictor of parental need for respite. Parents of educable mentally retarded children expressed less need for respite than parents of trainable mentally retarded, children eligible for day training and multiply handicapped children. The greater the degree of cognitive impairment, the more parents felt need for respite care. Bernheimer, et al. (1983) illustrated in their review of literature that parents seeking additional opinions are influenced by the nature of their children's handicapping conditions. A lack of specific diagnosis was problematic for parents and important in determining the time when professional support was received.

Research on social support illustrates that families of handicapped children are different in availability and satisfaction with social support depending on the child's age, transition, severity of disability, family income, and family status.

Stress and Social Support. There are two models addressing the relationship of stress and social support and other outcome variables (e.g. illness, parent participation): a) the main effect model, and b) the buffering model (Cohen, & Wills, 1985; Crnic, Greenberg, Robinson, & Ragozin, 1984). The main effect model states that an increase in social support will result in decreasing illness without showing a stress-social support interaction. The increase in social support will have a main effect on another outcome variable independent of the stress level. The buffering model examines the interaction of stress and social support with an outcome variable. These models are not mutually exclusive (Cohen & Wills, 1985). For the purpose of this study the buffering hypothesis was tested. First, the interaction of stress and social support was examined. Second, the contribution of stress and social support in predicting actual and needed parent participation was investigated.

There is ample evidence supporting the moderating effect of social support on stress (Cohen et al., 1985; Crnic et al., 1983; Crnic, Friedrich, & Greenberg, 1983; McKinney & Peterson, 1987; Friedrich & Friedrich, 1981; Friedrich, Wilturner, & Cohen, 1985; Dean & Lin, 1977; Dyson & Fewell, 1986; Gallagher, 1983: Meyer, 1986), which are discussed in detail in the following paragraphs.

In their longitudinal study of families of 44 preterm infants, Beckman and Pokorni (1988) investigated changes in stress and social support over the first two years. Informal support was significantly related to the amount of stress reported by parents at ages (3, 12, and 24 months) but not at 6 months. At 24 months stress was significantly negatively associated with informal support at each of the preceding ages. Informal support was the most persistent predictor of stress as measured by the QRS at 3 and 24 months.

As mentioned earlier, respite has been acknowledged as a special dimension of social support. Meyer (1986) investigated the relationship of stress in 120 families with mentally retarded children in northern New Jersey to parental needs for respite care. Stress related to having a handicapped child as measured by the Questionnaire on Resources and Stress (QRS) factor 3 (Limits on Family Opportunities) was found to be the best predictor of parental estimated need for respite care.

Dunst, et al. (1986) investigated mediating influences of social support on personal, family, and child outcomes of mentally retarded children. The sample consisted of 137 parents of mentally retarded, physically impaired, and developmentally atrisk preschool children. Social support moderated the effects of severity of disability on parental acceptance and behavior problems of children. Children with low developmental quotient scores were reported as being less socially accepted by the community. But, parents with more supportive social networks indicated that their children were more accepted. Negative effects on overprotection, family opportunities, high pessimism, more physical and behavior problems and lower developmental quotients were more likely to have occurred with increased child's age among families with minimum social support. Parents with a high number of and satisfaction with social support reported fewer physical and emotional health problems, fewer time demands placed on them, less protective behavior, and fewer restricted family opportunities as measured by subscales of the QRS (Dunst et al., 1986).

Friedrich and Friedrich (1981) investigated social assets of parents with handicapped children and parents with nonhandicapped children. Results indicate that parents with handicapped children face more stress and have fewer psychosocial assets (e.g. social support) available to ameliorate this additional stress. Friedrich (1981) found that parents of handicapped children did not lack social support. Friedrich et al. (1985) investigated coping resources of 158 parents of mentally retarded children. Social support, including intimate support, marital satisfaction, peer and friend availability and family support, were significantly related to QRSF factor 1 (Family/Parent Problems). A follow-up study with a subsample of 104 parents validated the results of the first study. In addition, a change in marital satisfaction (spousal support) resulted also in changes of family and parent problems.

A study on parents' reaction after the birth of a developmentally disabled child caused more symptoms of stress for mothers and fathers, depending on available social support. Fathers whose parents engaged in more activities with their child, felt more positive about their child, and were less pessimistic for the future; mothers who experience their in-laws as supportive had also more positive feelings about their child and consulted fewer doctors (Waisbren, 1980).

Sarason et al. (1983) examined the role of social support in laboratory situations when confronted with complex, partially insoluble, and frustrating problems. Social support in interaction with locus of control significantly related to both persistence and cognitive interference. In another substudy they found that people high in the number of social supports reported the occurrence of more positive life events than people low in social support; thus, in turn reducing the occurrence of negative life events such as stress

(Sarason, et al., 1985).

So far, studies on social support as a moderator of stress were reviewed. However, two studies address the moderating effect of social support on stress related to an outcome variable such as life satisfaction. Crnic et al. (1984) found that 105 mothers of infants with both high intimate and community social support and low stress have significantly greater life satisfaction, contentment with parenting, and more positive child rearing attitudes. Intimate support moderated the effect of high stress on life satisfaction. Sarason, et al. (1985) investigated the relationship of stressful life events, social support and the development of psychological and physical maladaptions. Subjects from a sample of 163 men with many life events and few social supports elicited a higher frequency of chronic illness than others. Subjects with many negative life events and low satisfaction with social support reported more isolated, chronic, and total illness.

The review of literature provided some evidence for the moderating effect of social support on stress. However, this relationship has been investigated with various concepts of stress and social support, different instruments and various samples.

Parent Participation and Potential Predictors

In the following paragraphs the literature on stress of parents with handicapped children and social support as possible predictors of parent participation is discussed.

Parent Participation, Stress, and Social Support.

The literature on needed parent participation has established that parents have individual preferences for the degree of participation in their child's program based on perceived benefit. According to LaCrosse (1982) it is essential that a needs assessment be implemented to insure that participation remains beneficial and does not become an additional problem for the family. MacMillan and Turnbull (1983) stated, "Consideration of whether to be actively involved in the educational program depends on a number of factors associated with the handicapped child and the family" (MacMillan & Turnbull, 1983, p. 7). An analysis of parent testimonials suggests that parental stress and social support are factors in explaining individual preferences for participation. That parents of handicapped children have unique levels of stress and social support has been demonstrated earlier. For some parents participation might be an additional source of stress; they would rather have a break from responsibilities, as one mother stated:

> A lot of times I get tired of having a role - God, I don't want to solve that - I'm paying you to take him for 3 hours and lady make it work. Maybe that's a nasty attitude toward teachers but I kind of feel that way sometimes. It's not worth it to me if I have to figure it out - I might as well have him with me at those times. (Winton & Turnbull, 1981, p. 15)

Respite has been previously defined as a form of social support. In this section, respite is put into context with schooling and parent participation.

A study on parents' perceptions on schooling of their severly handicapped children revealed that 86% of the parents preferred the respite value of having the child in school (Meyer & Blacher, 1987). Respite has been previously defined as a form of social support. Respite for parents as one function of public schooling is obvious: schools alone remove the burden of care from parents for 25 to 30 hours a week (Blacher & Prado, 1986). "The clear need for respite care, or time off from their responsibilities, seems to come into conflict with the professionals' expectations of the parent's participation in the program" (Gallagher et al., 1983, p. 16). While respite provides relief by removing the child from the family into school, parent participation might produce stress by removing the parent from the rest of the family or placing additional time-consuming responsibilities on the parent (Blacher & Prado, 1986). MacMillan and Turnbull (1983) stated that parents of handicapped children are often physically and emotionally exhausted, face tremendous stress (Gallagher, et al., 1983; Farber, 1959; Holroyd & McArthur, 1976; Friedrich & Friedrich, 1981) and, suffer from burn out as a result of constant caregiving demands (Beckman, 1983, 1988). All these factors alter their ability to be formally involved in their child's educational program. Turnbull (1985) illustrates the enormous amount of time she spent with advocating as a parent of a mentally retarded child:

> There was nothing normal about our schedules. We were not just consumers; rather we were consumed by the need to establish programs and services for Jay. When we reached the point of exhaustion and frustration, we realized that family priorities had to take precedence over advocacy needs. (Turnbull, 1985, p. 134)

In deciding about getting involved as a teacher of handicapped children, a parent activist stated, "Some handicapped children are so demanding and difficult that time spent with them detracts from the overall family welfare" (Schulz, 1982, p. 21). The existing relationship between child characteristics and stress as pointed out by Schulz (1982) has been reviewed earlier. Winton (1986) mentioned that families go through predictable and unpredictable events that disrupt established family routines and patterns because they are accompanied by a certain degree of stress. In the case of predictable events, social support systems can function as a moderator of stress in contrast to unpredictable events for which social networks seldom have any possibility to react and be helpful. Professionals providing parent participation options ought to know about these events accompanied with stress to accommodate for changes in participation activities. MacMillan & Turnbull (1983) also emphasized the availability and willingness of extended family to provide respite, and the availability of social support networks as important variables in determining the ability of parents to participate. Families differ in time and energy available to participate in the child's educational program; for some families the option not to be involved might be the most appropriate choice (Bowling Green State University, 1984; Winton & Turnbull, 1981). Comparing parents of handicapped children and nonhandicapped children, the latter face less stress during nonschool hours, and need not be so intensively involved at school (Gallagher et al., 1983; Farber, 1959; Holroyd & McArthur, 1976; Beckman, 1983; Friedrich & Friedrich, 1981; MacMillan & Turnbull, 1983). Therefore it is only natural, for some parents of handicapped children to question the value of additional participation (MacMillan & Turnbull, 1983). According to Bailey et al. (1986) reduced stress as a positive effect of family involvement in early intervention can only occur when involvement is individualized by following a goodnees-of-fit concept between characteristics of children and families and their coping demands. The sections on actual and needed parent participation revealed that parents are currently involved without considering individual parental needs, making it difficult to reduce stress via parent participation. Two empirical studies on perceived parental stress related to parent participation in the child's educational program are available. Lazar and Chapman (1972) concluded, that the most deprived and crisis-ridden parents are rarely involved in parent programs whereas the more stable and mobile families are typically involved. Barnes (1985) investigated the association of the newly introduced concept of critical times and parent participation. The concept of critical times is defined "as events or circumstances which are stressful for the parent and family unit..." (ibid., 1985, p. 35). Events that are qualifiying as "critical" are disruptive and would negatively affect the parent's ability to participate. Results indicate that a) participation was negatively related to reported critical times due to the disruptive effect of such stressful events; and b) the relationship of staff awareness of critical times and participation was positively but extremely weak. Although, a relationship of stress and parent participation is identified, the concept of critical times (e.g. alcoholism, health problem, hospitalization, death, unemployment; etc.) does not necessarily correspond with stress related to having a handicapped child. Also, the availability of and satisfaction with social support have not been included in Barnes' study.

The literature on social support, stress and parent participation is limited to a few studies and aforementioned testimonials, expressing the dilemma of parents need for respite while their child is in school and the professional's expectation to assume more responsibilities in participating in the child's educational program.

Some indication is given that stress and social support might be important variables accounting for individual differences in parent participation and its effect on the entire family. However, neither of the empirical studies on parent participation have measured parental stress related to having a handicapped child nor considered the availability of and satisfaction with social support.

Hypotheses

The following hypotheses are proposed for the purpose of investigating the research questions stated earlier in Chapter 1:

1) Parents' indication of availability of and satisfaction with social support will predict parental stress.
2) Parental stress, availability of and satisfaction with social support will predict actual parent participation.
3) Parental stress, availability of and satisfaction with social support will predict needed parent participation.
4) There will be a difference between reported actual and needed parent participation.

Operational Definitions

Stress, for the purpose of this study, is defined as the score obtained from the Questionnaire on Resources and Stress Friedrich (QRSF) (Friedrich et al., 1983).

Availability of and satisfaction with social support is defined according to the results of the Social Support Questionnaire Short-Revised (SSQSR) (Sarason et al., in press).

Actual and needed parent participation are operationally defined as the scores received from the Parent/Family Involvement Index (PFII) (Cone et al., 1984). The term "actual" is referred to as "...existing or acting at the time; present, current" (The Shorter Oxford English Dictionary, 1979, p. 20). The term "needed" refers to "desired," and "wanted," (Oxford Student's Dictionary of Anerican English, 1983, p. 397) or "required" (The Shorter Oxford English Dictionary, 1979, p. 1392).

Chapter 2

Method

Population and Sample

The sample in this study consisted of 100 parents of exceptional children across various handicapping conditions and age levels (ages 2 to 25 years). Parents were sought from several sources:

- Four hundred questionnaires were distributed to parents who were randomly selected from a list of 6,000 parents provided by the Central Office of Omaha Public Schools (OPS); 43 questionnaires were returned; 2 questionnaires were incomplete (return rate = 10.25 %);
- Twenty-four questionnaires were obtained from parents attending a Transition Fair at the University of Nebraska at Omaha;
- Selected principals in OPS distributed 23 questionnaires: 10 were completed and returned;
- 14 questionnaires were obtained from parents attending a Family Fair at Lewis and Clark Junior High School;
- Questionnaires were distributed in a University class by special education teachers. Of those distributed, 9 questionnaires were obtained.

Permission to use human subjects was obtained from the Institutional Review Board of the University of Nebraska. Each participating parent was asked to provide the following demographic data recorded on the "Demographic Data Sheet:"

Parent: -Sex, -Education, -Employment;
Child: -Age, -Sex, -Educational Program, Indication of Transition, -Severity of Disability;
Family: -Family Status, -Family Income.

The indication as to whether the child is currently in a transition phase was secured by providing parents 11 potential transition stages, adapted from Wikler (1981).

Instrumentation

Each participating parent completed one "Demographic Data Sheet," and three questionnaires: the Questionnaire on Resources and Stress Friedrich (QRSF), the Social Support Questionnaire Short-Revised (SSQSR), the Parent/Family Involvement Index (PFII).

The "Demographic Data Sheet" included a rating of the perceived severity of disability in seven functional areas (Appendix A).

Parents' actual and needed participation in their child's educational program was measured by utilizing the Parent/Family Involvement Index (PFII) (Cone et al., 1984). PFII is a 63-item measure, assessing the degree of parent participation in 12 conceivable involvement areas. The PFII was originally intended to measure the degree of parent participation as it is reported by parents or teachers. For the purpose of this study it was modified with permission of the author (Appendix D). The same statements were used with an additional set of instructions asking parents to report their needs for participation. The two scales of the PFII were named as APFII for actual parent participation and NPFII for needed parent participation. A high scorer agreement with a mean of 90% across the 12 areas of involvement was obtained. The internal consistency area and total scores was reliable (M = .81, range = .44 to .98 for area scores; KR-21 = .94 for total scores). For further information on the KR-21 values of area scores Table 11 (Appendix G) may be consulted. For the purpose of the study two reliabilty-tests were implemented: the reliability coefficient alpha was .93 for the APFII across 63 items. The internal reliability for the NPFII was .95 across 63 items. According to Cone, et al. (1985) correlations between area scores, total involvement score, teacher ratings, demographic and program characteristics indicated preliminary validity.

The Questionnaire on Resources and Stress-Friedrich (QRSF) (Friedrich et al., 1983) was derived from the

Questionnaire on Resources and Stress (QRS) (Holroyd, 1974) and resulted in a shorter inventory. The 285-item QRS was reduced in length to the 52-item QRSF, after removing the scales with low reliability: "lack of social support," "obstrusiveness," and "lie scale." A higher score on the QRSF indicates greater stress than a lower score. The QRSF addresses the following four factors: a) parent and family problems (20 items); b) pessimism (11 items); c) child characteristics (15 items); and, d) physical incapacitation (6 items). Parent-family problems (factor a) addresses the respondent's perception of problems for themselves, other family members, or the family as a whole. The central characteristic of pessimism (factor b) "...is an immediate and future pessimism about the child's prospects of achieving self-sufficiency (Friedrich, et al., 1983, p. 44)." Child characteristics (factor c) involve the parent's perception of behavioral or attitudinal problems displayed by the child. Physical incapacitation (factor d) addresses the parent's perception of limitations in the child's self-help skills and physical abilities. The QRSF is more suited than the longer QRS to allow main or interaction effects of social support (Friedrich et al., 1983: Cohen & Wills, 1985), because a confounding of the social support and the stress measure is emanated. With the QRS a confounding is likely to occur because the scale "Lack of Social Support" is measuring a similar construct as the social support measure. (Cohen & Wills, 1985). The internal consistency, measured with the Kuder-Richardson formula was .951 for the QRSF. Total scores correlated .997 with the total score of QRS (Friedrich, et al., (1983). Reliability testing for this study revealed an internal reliability of .92 for the QRSF. The concurrent validity of QRSF is indicated by the pattern of correlation with other independent measures such as the Beck Depression Inventory, the Marlowe-Crowne Social Desirability Scale, and the problem checklist (Friedrich et al., 1983). For further information on the concurrent validity of QRSF Table 14 (Appendix J) may be consulted.

The Social Support Questionnaire Short-Revised (SSQSR) (Sarason, Sarason, Shearin, & Pierce, in press) was derived from the 27-item Social Support Questionnaire (SSQ) (Sarason, Levine, Basham, & Sarason, 1983). The SSQSR grew out of a factor analysis resulting in 6 items. Each one asks a question to which a two-part answer is requested: a) the number of available others to whom the respondent can turn in given sets of circumstances (SSQSRN); and, b) an indication of satisfaction with available support (SSQSRS). The SSQSR is a measure of perceived rather than received social support. A study on the veridicality of social support indicated that people's perception of social support is even more important than their actual interpersonal contacts (Antonucci & Israel, 1986). Perceived social support was a better predictor of loneliness (Sarason, Shearin, Pierce, & Sarason, 1987) and well-being (Antonucci & Israel, 1986) than received social support. The internal reliabilities for the SSQSR ranged from .90 to .93 for both scales, availability and satisfaction. According to Sarason et al. (1983) the test-retest reliability was satisfactory. SSQSR and SSQ were compared to a varied group of social support indices (e.g. Social Network List). There were no significant differences between SSQSR and SSQ suggesting that the SSQSR is an acceptable substitute of SSQ. The internal reliability of the availability scale of the SSQ was .97, the test-retest reliability was .90. The internal reliability for the satisfaction scale was .94 with a test-retest reliability of .83 (Sarason, et al., 1983). For this study the internal reliability was .91 across both scales of the SSQSR. Sarason, et al. (in press) reported that the comparison of SSQSR and SSQ with individual difference variables (e.g. anxiety) revealed that the correspondence was quite close. However, scores were not reported.

Procedures

After OPS granted permission to implement this study, a letter of invitation (Appendix E) was mailed to 400 parents asking for their participation. A set of three questionnaires and one "Demographic Data Sheet" was enclosed. On a prestamped postcard parents were asked to indicate whether they would like to attend a meeting in one out of three high schools in order to complete questionnaires under supervision, or would like to get the questionnaires by mail. Except for three respondents, all parents requested the questionnaires per mail. Due to the low reponse rate, a follow-up letter (Appendix F) was sent to nonrespondents. Parents who asked for questionnaires but did not return them were phoned as a reminder. This procedure resulted in 28 returned sets of questionnaires. A second sampling from the list of 6,000 parents of OPS resulted in 15 additional returned questionnaires. The low response rate made the author change the recruitment of subjects.

The Department of Counseling and Special Education at the University of Nebraska at Omaha provided an exhibition table at a Transition Fair for parents of exceptional children. Parents walking by the table were informed about the purpose of the study and invited to participate. Assistance to complete questionnaires was provided for those parents interested in the study. Some parents preferred to have the questionnaire mailed to them. This resulted in 24 more sets of questionnaires. The distribution of questionnaires at a Family Fair at Lewis and Clark Junior High School and in University classes resulted in 23 additional returned questionnaires. An additional 10 sets were returned from distribution by principals in Omaha Public Schools.

Chapter 3

Results

The following section is a restatement of the hypotheses, a description of the way each was analyzed, and a presentation of results.

Description of the Study Population. Data gathered with the "Demographic Data Sheet" on the parent, the child, and the family unit for each of the 100 parents who took part in the study provided the basis for a description of a study population. These variables included parent's sex, education, employment, child's age, child's sex, educational program, indication of transition, severity of disability, family status, and family income. Demographic variables are also reviewed according to their relation to independent (QRSFA to QRSFD, SSQSRN, SSQSRS) and dependent variables (APFII, NPFII). With the exception of the child's age and family income, variables were asked in a multiple-choice manner. The data gathered are presented in Table 12 (Appendix H).

The study participants were predominately females who were 72% of the sample. The majority of parents had some college experience; 28% completed one to two years of college, 16% completed four years of college and 22% had done graduate work. Parents' education was significantly related to actual ($r = .2799$, $p < .002$) and needed parent participation ($r = .2405$, $p < .008$). Professionals and technical/trades employment represented 53% of the parent's work situations. An analysis of child variables showed that children ranged in age from 2 to 25 years, with the mean at 11.1 years and the mode at 12 years. The distribution by sex indicated that 63% of the children were male. The majority of children were either taught in special self-contained classrooms (9%), self-contained classrooms (32% + 10% of others = 42%) or in a regular classroom with additional instruction in resource rooms (33% + 1% of others = 34%). Of those remaining parents who chose the "other" option for their child's educational program, 3 were taught in preschool, 1 child received homebound instruction and 1 child was taught in an alternative school. The analysis of family variables indicates that 80% of parents were married, 12% of parents were widowed, 7% of respondents were single, with one parent being divorced. The incomes of families when categorized represented a symmetrical distribution with the income mean of $ 27,379. However, 11% of parents chose not to answer this question.

Parents' perceived severity of disability of 100 subjects are listed in Table 13 (Appendix I). For the purpose of clarity the parent's severity ratings were summed. Based on the sums five categories were established.

Table 1

Parents' perceived Severity of Disability across Functional Areas

Severity Sums	*N* = *%*
No significant problem	3
Mild: 01-07	48
Moderate: 08-14	43
Severe: 15-21	6
Profound: 22-28	0

Data in Table 1 indicate that the majority of parents perceived their child in the mild to moderate group of severity. However, these categories are not comparable to those commonly used for labels in special education because they address a summed severity across functional areas. To illustrate the magnitude of these categories, an example is given. One parent perceived his child belonging to the moderate group as 50% to 74% visually functional, with normal hearing, 25% to 49% physically able, 50% to 74% functional in social matters, 50% to 74% functional in using language, 75% to 90% mentally functional, and 50% to 74% behaviorally functional.

The literature stated that severity of disability is related to stress and social support. For this purpose a Pearson Product-Moment correlation was implemented.

Table 2

<u>Correlation Matrix: Parents' perceived Severity of Disability related to Stress and Social Support</u>

Variables	*r*	*p*
	Stress	
Parent and Family Problems	.5046	< .0005
Pessimism	.6837	< .0005
Child Characteristics	.6402	< .0005
Physical Incapacitation	.3084	< .001
	Social Support	
Availability	-.2896	< .002
Satisfaction	-.3401	< .0005

A typing error on the severity rating scale was made. The category of mild problems was described as 75-99% functional rather than 75-90%. Due to this error it might have been that parents were less inclined to mark the first category of the severity scale, which was named as "100% functional." However, it is also possible that parents looked at words (e.g. mild, moderate, severe, profound) rather than percentages of functionality. Nevertheless, results tend to indicate a significant relationship between the severity of disability and stress and social support variables (Table 2). The more severe the child's handicap the greater the stress level of parents. However, further investigation on this issue is needed. The greater parents' satisfaction with and availability of social support the lower was their perception of the severity of their child's handicap.

The "Demographic Data Sheet" asked parents to indicate as to whether they perceived their child in one or more transition stages of life. Ten transition stages and one non-transition option were given to parents for selection. Of 100 parents, 82% indicated that they perceived their child and the family being in one or more transition stage/s: 11% indicated that they are not in a transition stage; and 7% chose not to answer this question. An analysis of transition stages revealed that 49% of families faced more than one transition stage, 31% of families dealt with more than two transition stages, 18% faced more than three transition stages, 12% dealt with more than four transition stages, 5% of parents perceived being in more than five stages; and 1% face more than six transition stages at the same time.

A Bonferroni Adjustment resulted in an alpha level of .0038 to test the hypotheses in this study.

Hypothesis 1

Parents' indication of availability of and satisfaction with social support will predict parental stress. Availability of and satisfaction with social support was measured with the SSQSRN and SSQSRS respectively. Parental stress was measured with the four factors of QRSF: QRSFA, QRSFB, QRSFC, QRSFD, and a total score. A multiple regression analysis was used to analyze the predictability of parental stress by utilizing the SSQSRN and SSQSRS as predictors. Five regression models were developed with availability of social support (SSQSRN) and satisfaction with social support (SSQSRS) as independent variables having each of the four stress factors (QRSFA, QRSFB, QRSFC, QRSFD) and the total score (QRSF) as dependent variables.

Table 3

Multiple Regression Analysis on the QRSF Total Score and Four Factors.

Independent Variables	B	SE B	BETA	t	SIG t
Total Score (QRSF)					
SSQSRS	-2.57366	.8592	-.29813	-2.995	.0035
SSQSRN	-1.36779	.498	-.27338	-2.747	.0072
(CONSTANT)	34.63783	3.98541		8.691	.00005
Parent and Family Problems (QRSFA)					
SSQSRS	-1.49841	.38294	-.36143	-3.913	.0002
SSQSRN	- .7821	.22195	-.32549	-3.542	.0007
(CONSTANT)	15.51196	1.77618		8.733	.00005
Pessimism (QRSFB)					
SSQSRS	- .48545	.29867	-.17207	-1.625	.1073
SSQSRN	- .42478	.1731	-.25977	-2.454	.0159
(CONSTANT)	9.07603	1.38531		6.552	.00005
Child Characteristics (QRSFC)					
SSQSRS	- .5132	.29594	-.19136	-1.731	.0866
SSQSRN	- .13739	.17152	-.08854	- .801	.4251
(CONSTANT)	8.00092	1.37267		5.829	.00005
Physical Incapacitation (QRSFD)					
SSQSRS	- .07747	.11051	-.07948	- .701	.4849
SSQSRN	- .02352	.11051	-.07948	- .361	.7142
(CONSTANT)	2.04893	.51256		3.997	.0001

Multiple Regression on Parent and Family Problems (QRSFA). Satisfaction (SSQSRS) with and availability (SSQSRN) of social support accounted for a significant proportion of the prediction variance, $R^2 = .344$, $F = 25.38$, $p < .00005$. As shown in Table 3 the beta weights indicate that satisfaction with and availability of social support contributed significantly to nearly the same extent to the variance.

Multiple Regression on Pessimism (QRSFB). Satisfaction (SSQSRS) with and availability of (SSQSRN) social support accounted for a significant size of total variance to predict pessimism, $R^2 = .138$, $F = 7.75$, $p < .0008$. Beta weights in table 3 illustrate that availability of social support added more to the prediction than satisfaction with social support.

Mulitple Regression on Child Characteristics (QRSFC). Neither social support variables accounted for a significant contribution to predict parents' perception of behavioral or attitudinal problems presented by the child, $R^2 = .06$, $F = 3.09$, $p < .0501$.

Multiple Regression on Physical Incapacitation (QRSFD). The contribution of social support to predict parents' perception of physical incapacitation of their child was not significant, $R^2 = .011$, $F = .54$, $p < .583$.

Multiple Regression on the total score of QRSF. Satisfaction with and availability of social support predicted a significant proportion of the QRSF total score, $R^2 = .237$, $F = 15.12668$, $p < .00005$. Beta weights denote that satisfaction with and availability of social support contributed nearly to the same extent.

Hypothesis 2

Parental stress, availability of and satisfaction with social support will predict actual parent participation. Actual parent participation was measured with the APFII. A multiple regression analysis was done entering the total score of actual parent participation (APFITOT) as a dependent variable and the following independent variables: SSQSRN, SSQSRS, QRSFA to QRSFD into the equation.

Table 4

Multiple Regression Analysis: Predicting Actual Parent Participation.

Independent Variables	B	SE B	BETA	t	SIG t
		Social Support			
SSQSRN	.0232	.01115	.24984	2.08	.0403
SSQSRS	.02172	.01926	.13556	1.128	.2623
		Stress			
QRSFA	.01005	.00592	.26003	1.698	.0928
QRSFB	.00554	.00331	.09754	.667	.5067
QRSFC	-.01199	.00834	-.20044	-1.438	.1538
QRSFD	.00479	.01815	.02914	.261	.7924
(CONSTANT)	.22036	.11261		1.957	.0534

All independent variables accounted for merely 8.78% of the total prediction variance without reaching significance; $F = 1.4925$, $p < .189$ (Table 10). As illustrated in Table 4 the standard regression coefficient indicates that "availability of social support" was closest to contributing to the equation in a significant manner (beta = .24984, $t = 2.08$, $p < .0403$).

Thus, social support and stress of parents of handicapped children did not predict their actual degree of participation in their child's educational program.

Hypothesis 3

Parental stress, availability of and satisfaction with social support will predict needed parent participation. Needed parent participation was measured with the NPFII, the second scale of the adapted PFII. Using a multiple regression forced-entry format, the total score of the NPFII was entered as a dependent variable. The independent variables QRSFA, QRSFB, QRSFC, QRSFD, SSQSRN and SSQSRS were entered simultaneously into the equation.

Table 5

Multiple Regression: Predicting Needed Parent Participation.

Independent Variables	B	SE B	BETA	t	SIG t
			Social Support		
SSQSRN	.0048	.01417	.04171	.338	.7358
SSQSRS	.00894	.02447	.04505	.365	.7158
			Stress		
QRSFA	.00761	.00752	.15894	1.011	.3145
QRSFB	.00243	.01056	.03452	.230	.8187
QRSFC	-.01082	.0106	-.14596	-1.020	.3102
QRSFD	.02761	.02306	.13565	1.197	.2343
(CONSTANT)	.55427	.14309		3.873	.0002

The independent variables accounted for only 3.94% of the total variance to predict parental needs for participation; F = .6364, p < .7008 (Table 10). Thus, hypothesis 3 has to be rejected: parental stress and social support are not valid predictors of needed parent participation. As Table 5 indicates none of the independent variables contributed significantly to the variance of needed parent participation.

Hypotheses 4

There will be a difference between reported actual and needed parent participation. Actual parent participation was represented by the total score (APFITOT) and the overall rating (APFIO) of the PFII. Needed parent participation was measured with the total score (NPFITOT) and the overall rating (NPFIO) of the PFII. For the purpose of testing this hypothesis a t test was implemented. If two sets of scores need to be compared, the significance of the difference of means by considering the standard error of the mean difference is the most satisfactory measure (Best & Kahn, 1986), thus the selection of a t test. Thus, the means of the total score and overall rating of the APFII were compared to the NPFII.

Overall ratings of actual and needed parent participation. Although scores of overall actual and needed parent participation were different (see Table 6) in that a higher overall involvement was desired, this could have occurred by chance ($p < .020$). Because the overall rating is merely a number assigned from 1 to 6 on one item, this result is not considered to be as decisive as the total score.

Total scores on actual and needed parent participation. The total scores reflect the degree of participation across 12 involvement areas including 63 involvement activities. As shown in Table 6 there was a significant difference in total scores of actual vs. needed participation. Parents would like to be involved to a higher degree than they actually are. Results do support Hypothesis 4.

Table 6

Comparison of Mean Scores Between Actual and Needed Parent Participation.

Participation Variables	N	M	SD	t	p
APFIO	100	3.67	1.356	-2.37	.020
NPFIO	100	4.01	1.439		
APFITOT	100	.4376	.194	-10.39	.0005
NPFITOT	100	.6587	.241		

Chapter 4

Interpretation of Results

Discussion

Parents in this study reported heightened stress levels compared to other studies that utilized the QRSF as a stress measure. Even though comparable studies are rare, Table 7 offers some support for this notion.

Table 7

Comparison of QRSF Mean Scores and Standard Deviations of Different Studies.

Study:	Schlosser (1988)		Friedrich et al. (1985)				Dyson & Fewell (1986)			
Population:	Handicapped		Handicapped				Handicapped		Nonhandicapped	
Mean Age	11.1		10.5		11.0		4.8		4.7	
QRSF	M	SD	M	SD	M	SD	M	SD	M	SD
Parent and Family Problems (QRSFA)	5.36	5.03	4.1	4.0	6.2	4.0	3.4	2.82	2.73	2.43
Pessimism (QRSFB)	5.22	3.42	not measured				2.87	2.36	.93	1.22
Child Characteristics (QRSFC)	4.96	3.25	not measured				3.13	1.36	.87	.99
Physical Incapacitation (QRSFD)	1.58	1.18	not measured				2.47	1.69	.67	.82

Results for Hypothesis 1 offer additional evidence for social support as a moderator and predictor of stress in a heretofore untested population as far as the variety of handicapping conditions, the severity of disability, and the child's age level is concerned. Studies have been focusing on nonhandicapped infants and preschoolers or infants with developmental disabilities (Crnic, et al., 1984; Dunst, et al., 1986; Dyson & Fewell, 1986; Beckman & Pokorni, 1988; McKinney & Peterson, 1987). Although Friedrich et al. (1985) discerned a moderating effect of spousal support in two studies with parents of 10.5 and 11.0 year old mentally retarded children, parental stress was only measured for parent and family problems (QRSFA).

Social support in this thesis study (Mean age = 11.1 years) was a significant predictor of QRSFA, QRSFB, and the total score of QRSF. Social support was best at predicting respondents' perception of parent and family problems (QRSFA) accounting for 34.4% of the total variance; second ranked was the prediction of the QRSF total score explaining 23.7% of the variance; and third in order was the prediction of parents' pessimism about the child's chances to achieve self-sufficiency (QRSFB) accounting for 13.8% of the variance.

Table 8

Social Support as a Predictor of Stress: R^2-Values.

Dependent Variables	R^2
Parent and Family Problems (QRSFA)	.344
Pessimism (QRSFB)	.138
Total (QRSF)	.237

Results are consistent with research on social support as a predictor of stress in families with infants or preschool handicapped children (McKinney & Peterson, 1987; Beckman & Pokorni, 1988).

Because of a modest correlation between the availability of and satisfaction with social support, Sarason, et al. (1983) suggest that both subscales are tapping different aspects of social support and each appear to be worthy of analysis. Considering the prediction of the QRSF total score, satisfaction with and availability of social support contributed close the same amount of the equation (Table 3). However, the availability of social support explained more of the variance in predicting parental pessimism (QRSFB), supporting Sarason's et al. (1983) argument that satisfaction with and the number of social support are apt to differently predict various facets of stress.

Parents' reports of transition stages suggest that parents dealt concurrently with multi-transition stages, bearing important implications for the periodicity theory of stress (Wikler, 1986; Wikler, et al., 1981). As mentioned earlier, this theory states that certain periods in the life cycle of families with a handicapped child may result in more stress than other periods. Results in this study strongly suggest that for some parents these periods are made up of multiple transition stages rather than one transition stage.

Results strongly validate Hypothesis 4. There was a difference in reported actual participation and needed parent participation; parents reported wanting to be involved in their child's educational program to a higher degree than they actually are. This significant difference was even maintained when mothers' and fathers' participation was considered individually. The following table allows insight in similarities and differences between this study and a field-test by Cone et al. (1985).

Table 9

Comparison of Parent Participation Results with Cone's Study.

Participation Variables	Schlosser (1988) Mothers N = 72		Schlosser (1988) Fathers N = 28		Cone et al. (1985) Mothers N = 226		Cone et al. (1985) Fathers N = 168	
	M(%)	SD	M(%)	SD	M(%)	SD	M(%)	SD
APFIO	3.75	1.42	3.46	1.17	2.8	1.3	1.8	1.1
NPFIO	4.08	1.45	3.82	1.42	not measured			
APFITOT	45.00	19.20	40.58	20.00	35.8	22.2	16.7	18.3
NPFITOT	68.1	23.2	60.2	25.8	not measured			

Considering overall ratings and total scores, mothers as well as fathers in this study perceived themselves as being more involved than teachers' ratings of parents' participation in Cone's et al. (1985) study. So far, differences in teachers' perceptions and parents' perceptions of parent participation have not been addressed by research. The author of this study assumes that parents' perceptions of participation will become even more important with the development of individualized and family-focused parent participation. The high degree of involvement of parents supported by data in this sample is also reflected by their willingness to participate in this study; completing three questionnaires of which one was quite comprehensive and a demographic data sheet required high interest in parent participation. Although the results do support Cone's et al. (1985) observation that mothers are more involved than fathers, the differences in this sample are small. So far, the evidence of actual low participation (Salett & Henderson, 1980; Yoshida et al., 1978; Goldstein et al., 1980; Lynch & Stein, 1980; Cone et al., 1985) has been leading to the nondata-based conclusion that parental needs were not met (Winton, 1986). The tremendous difference in total scores of actual and needed parent participation of approximately 22% (mothers = 23.1%, fathers = 19.62%) provides data-based support for this nondata-based statement; perceived parental needs were not being met. Although, from the researcher's point of view parents' participation in this sample is regarded as fairly high, parents themselves still perceived it as low compared to their needs. Similar to Cone's et al. (1985) study, parents' educational level was positively related to the total involvement score (APFITOT = .28, p < .002, NPFITOT = .24, p < .008), although the correlation coefficent in Cone's et al. (1985) study was higher.

Parental stress and social support were neither significant predictors of actual participation nor needed parent participation (Table 10).

Table 10

Stress and Social Support as Predictors of Actual and Needed Parent Participation: R^2-Values

Dependent Variables	Actual Participation R^2	F	p	Needed Participation R^2	F	p
Stress & Social Support	.0878	1.4925	.189	.0394	.6364	.7008

However, there might be some potential explanations for this result. As discussed earlier, parents have had to face a high level of stress associated with having a handicapped child. Despite this fact there was only a negligible correlation between stress, actual and needed parent participation found. Assuming that parents wanted to consider their individual resources and stress while rating their actual participation, professionals would still have to accommodate the differences in parent stress and social support. The phenomenon of parent participation depends on parents who are willing to participate and professionals who are willing to provide individual parent participation options. But, the review of literature revealed that individual preferences for parent involvement are rarely taken into account (Turnbull & Turnbull, 1982; Winton & Turnbull 1983); which might reduce the likelihood of stress and social support as predictors of actual participation. Nevertheless, stress and support predicted neither actual nor needed parents' participation, although needed participation is independent from professionals' provision of individual participation options. Parents might have rated participation needs in terms of "benefits" for their child and social desirability rather than feasibility in regard to their family's resources and stress level. This would reflect current parent participation practices with a focus on the child rather than the family as a system. Based on this assumption, not merely professionals need to acquire new skills and perspectives about parent participation, but also parents themselves. Although many parent testimonials do indicate the necessity of a family systems approach and respect for individual preferences, this awareness and critique on the current state of participation seems to be restricted to so-called "professional" parents rather than the typical parent. "Professional" parents are highly involved in their child's educational program. Some "professional" parents work in the field of special education besides being a parent of a handicapped child (e.g. A. P. Turnbull, J. B. Schulz).

It might be more likely that typical parents would consider their participation needs in terms of feasibility when asked to weigh their participation choices in regard to their resources and stress levels.

The procedures of implementing PL 99-457, particularly the multidisciplinary assessment of individual family needs, are not yet clear (Vincent & Salisbury, 1988). This study bears important implications to implement PL 99-457. Social support proved to be a moderator and predictor of heightened parent stress levels related to having a handicapped child. In order to provide tailored family services that supplement not supplant each family's resources, social support and stress in families with young handicapped children need to be assessed. Social Support was apt to predict differently various aspects of stress, such as parent and family problems, parents' pessimism, and the total score of the QRSF. However, social support predicted neither parents' perceptions of behavioral and attitudinal problems presented by the child (QRSFC) nor parents' perceptions of physical incapacitation (QRSFD). These findings seem to indicate that family focused services should address parents' perceptions of child characteristics and physical incapacitation more extensively by means of professional social support. The remarkable differences between parents' perceptions in this study and teachers' ratings of parent participation in Cone's et al. (1985) study strongly suggest an assessment procedure based on parents' perceptions rather than teachers' ratings. In order to get parents to rate their participation needs in terms of feasibility in regard to their resources and stress levels, current assessment instruments ought to be modified.

Limitations

Parents in this study demonstrated high interest in their child's education just by participation in the study, because the completion of questionnaires was quite time-consuming. The completion of all three questionnaires and the "Demographic Data Sheet" required approximately 45 minutes. The return rate of 10.25% for the first mailing might be an indication that those parents who participated were highly motivated. Also, parents in this study reported a fairly high level of education. In contrast to the literature on family status (US Bureau of the Census, 1984; Rawlings, 1980) only 7 respondents were single parents. Unusual is the representation of widows (12%) among participants. The respondents' high motivation, high level of education, and the low number of single parents need to be considered when generalizing results of this sample.

Conclusions

The validation of Hypothesis 1 that social support is a significant predictor of parental stress related to having a handicapped child has important implications for the implementation of PL 99-457, particularly the development of the Individualized Family Service Plan (IFSP). Any assessment of individual family strengths and needs must include parents' stress level and their availability of and satisfaction with social support as a foundation to support the family role wherever it is necessary. Information on social support as a predictor of stress could be utilized to plan with families proactively rather than in reaction to stress.

Results allow the conclusion that parental needs for participation are far from being met. The necessity of needs assessment for participation is highly suggested. Studies focusing on actual participation are not sufficient to draw any conlusions for needed parent participation.

Parental stress and social support could neither predict actual participation nor needed parent participation in this study.

Implications for Further Research

Further research on the relationship of stress and social support should be longitudinal in nature, measuring stress and social support at different times. It might be worthwhile to replicate this study with other social support measures to identify the most suitable conceptualization of social support for parents of handicapped children. Research might also address the influence of multiple transition stages on parent stress.

Research addressing actual and needed parent participation should focus on discrepancies and consistencies at the level of involvement areas rather than total involvement scores. This would have been beyond the scope of a thesis project. As mentioned earlier, parents might have rated participation needs in terms of "benefits" for the child and an idealistic perspective rather than feasibility in regard to their resources and stress. Future research on needed parent participation might focus on the development of an instrument asking parents to weigh their participation choices in terms of feasibility (e.g. commitment, time, energy, resources).

The relationship of stress, social support, and actual versus needed participation requires further investigation. Using involvement area scores rather than total scores as dependent variables in multiple regression analyses may yield interesting data. It is likely that time-consuming involvement areas that require more committment (e.g. advocacy, classroom volunteering) are better predicted by stress and social support than less demanding involvement activities (e.g. transportation).

It further needs to be investigated whether the involvement area "Parent-Parent Contact and Support" interfered with the social support measure.

Allen, D. A., & Hudd, S. S. (1987). Are We Professionalizing Parents? Weighing the Benefits and Pitfalls. Mental Retardation, 25(3), 133-139.

Antonucci, T. C., & Israel, B. A. (1986). Veridicality of Social Support: A Comparison of Principal and Network Members' Responses. Journal of Consulting and Clinical Psychology, 54(4), 432-437.

Ary, D., Jacobs, L. C., & Razavieh, A. (1979). Introduction to Research in Education. New York: Holt, Rinehart and Winston.

Bailey, D. B., Simeonsson, R. J., Winton, P., Huntington, G. S., Comfort, M., & Isbell, P. (1986). Family-Focused Intervention: A Functional Model for Planning, Implementing, and Evaluating Individualized Family Services in Early Intervention. Journal of the Division for Early Childhood, 10(2), 156-169.

Barnes. N. G. (1985). The Influence Of Staff Awareness Of And Response To Stressful Events For Parents And Their Program Participation. UMI Dissertation Information Service. (University Microfilms International, No. 8518223).

Beckman, P. J. (1983). Influence of Selected Child

Characteristics on Stress in Families of Handicapped Infants. American Journal of Mental Deficiency, 88(2), 50-56.

Beckman, P. J., & Pokorni, J. L. (1988). A Longitudinal Study Of Families Of Premature Infants: Changes In Stress And Support Over The First Two Years. The Journal of Special Education, 22(1), 55-65.

Bernheimer, L. P., Young, M. S., & Winton, P. J. (1983). Stress Over Time: Parents with Young Handicapped Children. Developmental And Behavioral Pediatrics, 4(3), 177-181.

Best, J. W., & Kahn, J. V. (1986). Research in Education (5th ed). Englewood Cliffs: Prentice Hall.

Blacher, J., & Prado, P. (1986). The School as Respite For Parents Of Children With Severe Handicaps. In C. L. Salisbury, & J. Intagliata (Eds.). Respite Care: Support for Persons with Developmental Disabilities and Their Families. (pp. 217-234). Baltimore: Paul H. Brooks.

Bowling Green State University (Ed.) (1984). Individualizing Parent & Professional Partnerships (IPPP). Handbook September 1, 1983-August 31, 1981. Columbus, OH: Department of Special

Education. (ERIC Document Reproduction Service No. ED 257 245).

Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Cambridge: Harvard University Press.

Cieslewitcz, M. M. (1985). The Effects of Parent Participation and Training in Educational Programming on the Developmental Achievement of Handicapped Children: A Review of the Literature. ERIC Document Reproduction No. ED 268 710.

Cohen, S., & Wills, T. A. (1985). Stress, Social Support, and the Buffering Hypothesis. Psychological Bulletin, 98(2), pp. 310-357.

Cone, J. D., Wolfe, V. V., & Delawyer, D. D. (1984). Parent/Family Involvement Index (P./F.I. I.). The Virginia System, Working Paper # 10.

Cone, J. D., Delawyer, D. D., & Wolfe, V. V. (1985). Assessing Parent Participation: The Parent/Family Involvement Index. Exceptional Children, 51(5), 417-424.

Crnic, K. A., Greenberg, M. T., Ragozin, A. S., & Robinson, N. M. (1981) Inventory of Parents' Experiences. Unpublished Rating scales. Department of Psychiatry and Behavioral Sciences. University of Washington, Seattle.

Crnic, K. A., Friedrich, W. N., & Greenberg, N. T. (1983). Adaption of families with mentally retarded children: A model of stress, coping, and family ecology. American Journal of Mental Deficiency, 88(2), 125-130.

Crnic, K. A., Greenberg, M. T., Robinson, N. M., & Ragozin, A. S. (1984). Maternal Stress and Social Support: Effects on the Mother-Infant Relationship from Birth to Eighteen Months. American Journal of Orthopsychiatry, 54(2), 224-235.

Cummings, S. T. (1976). The Impact Of The Child's Deficiency On The Father: A Study of Fathers of Mentally Retarded and of Chronically Ill Children. American Journal of Orthopsychiatry, 46(2), 246-255.

Dean, A., & Lin, N. (1977). The Stress-Buffering Role Of Social Support. Journal Of Nervous And Mental Disease, 165(6), 403-417.

Dunst, C. J. & Trivette, C. M., Cross, (1986). Mediating Influences of Social Support: Personal, Family, and Child Outcomes. American Journal of Mental Deficiency, 90(4), 403-417.

Dyson, L., & Fewell, R. R. (1986). Stress and Adaption in Parents of Young Handicapped and

Nonhandicapped Children: A Comparative Study. _Journal of the Division for Early Childhood_, _10_(1), 25-35.

Etheridge, G. W. (1980). _Home-School Relations: Together We Stand Or Divided We Fail_. (ERIC Document Reproduction Service No. ED 175 144).

Farber, B. (1959). Effects of a severely retarded child on family integration. _Monographs of the Society for Research in Child Development_, 24 (2, Serials No. 71).

Federal Register (1981). _U.S. Government Printing Office_, January 19, 1981, Washington, DC.

Folkman, S., Schaefer, C., & Lazarus, R. C. (1979). Cognitive processes as mediators of stress and coping. In V. Hamilton & D. W. Warburton (Eds.), _Human Stress and Cognition_. New York: John Wiley.

Friedrich, W. N. (1981). Predictors of coping behaviors of mothers of handicapped children. _Journal of Consulting Psychology_, 47, 1140-1141.

Friedrich, W. N., & Friedrich, W. L. (1981). Psychological Assets of Parents of Handicapped and Nonhandicapped Children. _American Journal of Mental Deficiency_, _85_(5), 551-553.

Friedrich, W. N., Greenberg, M. T, & Crnic, K. A.

(1983). A Short-Form of the Questionnaire on Resources and Stress. American Journal of Mental Deficiency, 88(1), 41-48.

Friedrich, W. N., Wilturner, L. T., & Cohen, D. S. (1985). Coping Resources and Parenting Mentally Retarded Children. American Journal of Mental Deficiency, 90(2), 130-139.

Gallagher, J. J., Beckman, P., & Cross, A. H. (1983). Families of Handicapped Children: Sources of Stress and Its Amelioration. Exceptional Children, 50(1), 10-19.

Garbarino, J., Gaboury, M. T., Long, F., Grandjean, P., & Asp, E. (1982). Who Owns the Children? An Ecological Perspective On Public Policy Affecting Children. Child & Youth Services, 5, 43-63.

Gilliam, J. E., & Coleman, M. C. (1981). Who Influences IEP Committee Decisions? Exceptional Children, 47(8), 642-644.

Glass, G. V., & Stanley, J. C. (1970). Statistical Methods in Education and Psychology. Englewood Cliffs, NJ: Prentice-Hall, Inc.

Goldstein, S., Strickland, B., Turnbull, A. P., & Curry, L. (1980). An Observational Analysis of the IEP Conference. Exceptional Children, 46(3), 279-287.

Guralnik, D. B. (Ed.). (1984). Webster's New World Dictionary (2nd College Edition). New York: Simon and Schuster.

Hoff, M. K., Fenton, K. S., Yoshida, R. K., & Kaufman, M. J. (1978). Notice and Consent: The School's Responsibility To Inform Parents. Journal of School Psychology, 16(3), 265-273.

Holroyd, J. (1974). The Questionnaire on Resources and Stress: An Instrument to measure family response to a handicapped family member. Journal of Community Psychology, 2, 92-94.

Holroyd, J., Brown, N, Wikler, L., & Simmons, J. Q. (1975). Stress in Families of Institutionalized and Noninstitutionalized Autistic Children. Journal of Community Psychology, 3, 26-31.

Holroyd, J., & Guthrie, D. (1979). Stress in Families with Neuromuscular Disease. Journal of Clinical Psychology, 35(4), 734-739.

Holroyd, J. & Guthrie, D. (1986). Family Stress with Chronic Childhood Illness: Cystic Fibrosis, Neuromuscular Disease, and Renal Disease. Journal of Clinical Psycholgy, 42(4), 552-561.

Holroyd, K. A., & Lazarus, R. S. (1982). Stress, Coping, and Somatic Adaption. In Goldberger & S.

Brezwitz (Eds.), Handbook of Stress: Theoretical and clinical aspects. New York: Free Press.

Holroyd, J., McArthur, (1976). Mental Retardation and Stress on the Parents: A Contrast between Down's Syndrome and Childhood Autism. American Journal of Mental Deficiency, 80(4), 431-436.

Hornby, A. S., Harris, D., & Stewart, W. A. (Eds.). (1983). Oxford Student's Dictionary of American English. Oxford, New York: Oxford University Press.

Kerlinger, F. N., & Pedhazur, E. J. (1973). Multiple Regression in Behavioral Research. New York: Holt, Rinehart and Winston.

LaCrosse (Ed.) (1982). Parent Involvement. (ERIC Document Reproduction Service No. ED 221 973).

Lazar, J. B., & Chapman, J. E. (1972). A review of the Present Studies and Future Research Needs of Programs to Develop Parenting Skills. Washington D.C. (ERIC Document Reproduction Service No. ED 068 150).

Lynch, E. W., & Stein, R. (1982). Perspectives on parent participation in special education. Exceptional Education Quarterly, 3(2), pp. 55-63.

MacMillan, D. L., & Turnbull, A. P. (1983). Parent Involvement with Special Education: Respecting Individual Preferences. Education and Training of the Mentally Retarded, 18(1), 4-9.

Mandell, C. (1984). Developing individualized parent participation programs: Final Report. Bowling Green, OH: Bowling Green State University.

McAfee, J. K., & Vergason, G. A. (1979). Parent Involvement in the Process of Special Education: Establishing the New Partnership. Focus On Exceptional Children, 11(2), pp. 3-15.

McCubbin, H., Joy, C., Cauble, A. E., Commean, J., Patterson, J., & Needle, R. (1980). Family Stress and Coping: A decade review. Journal of Marriage and the Family, 855-871.

McKinney, B., & Peterson, R. A. (1987). Predictors of Stress in Parents of Developmentally Disabled Children. Journal of Pediatric Psychology, 12(1), 133-150.

Meyer, S. (1986). The Relationship of Characteristics of Handicapped Children And their Families To Parental Need for Respite

Care. UMI Dissertation Information Service. (University Microfilms International, No. 8611687).

Meyer, C. E., & Blacher, J. (1987). Parents' Perceptions of Schooling for Severely Handicapped Children: Home and Family Variables. Exceptional Children, 53(5), 441-449.

Mills vs. Board of Education of the District of Columbia, (1972). (348 F. Suppl. 866) CD.D.C.

Mitchell, R. E., & Trickett, E. J., (1980). Task force report: social networks as mediators of social support. Community Mental Health Journal, 16, 27-43.

Pearson, E. S., & Hartley, H. O. (Eds.). (1972). Biometrik Tables For Statisticians (Vol 2). Cambridge: University Press.

Posante-Loro, R. (1978). Factors Associated with Parent Satisfaction with a Preschool Program for the Handicapped. Unpublished doctoral dissertation, University of North Carolina at Chapel Hill.

Public Law 94-142, Education for All Handicapped Children Act, (1975). November 29.

Rawlings, S. W. (1980). Families maintained by female housholders, 1970-1979. In US. Bureau of the Census, Current Population Reports, Series P-23, No. 107, 1980.

Salett, S. & Henderson (1980). A Report on the Education for All Handicapped Children Act: Are Parents Involved? (ERIC Document Reproduction Service No. ED 209 183).

Salisbury, C. L. (1986). Parenthood And The Need For Respite. In C. L. Salisbury & J. Intagliata (Eds.). Respite Care: Support for Persons with Developmental Disabilities and Their Families. (pp. 3-21). Baltimore: Paul H. Brooks.

Salisbury, C. L. (1987). Stressors of Parents with Young Handicapped and Nonhandicapped Children. Journal of the Division for Early Childhood, 11(2), 154-160.

Sarason, B. R., Sarason, I. G., Hacker, F. A., & Basham, R. B. (1985). Concomitants of Social Support: Social Skills, Physical Attractiveness, and Gender. Journal of Personality and Social Psychology, 49(2), 469-480.

Sarason, B. R., Shearin, E. N., Pierce, G. R., & Sarason, I. G. (1987). Interrelations of Social Support Measures: Theoretical and Practical Implications. Journal of Personality and Social

Psychology, 52(4), 813-832.

Sarason, I. G., Levine, H. M., Basham, R. B., & Sarason, B. R. (1983). Assessing Social Support: The Social Support Questionnaire. Journal of Personality and Social Psychology, 44(1), 127-139.

Sarason, I. G., Sarason, B. R., Potter, E. H., & Antoni, M. H. (1985). Life Events, Social Support and Illness. Pschosomatic Medicine, 47(4), 156-163.

Sarason, I. G., Sarason, B. R., & Shearin, E. N. (1986). Social Support as an Individual Difference Variable: Its Stability, Origins, and Relational Aspects. Journal of Personality and Social Psychology, 50(4), 845-855.

Sarason, I. G., Sarason, B. R., Shearin, E. N., Pierce, G. R. (in press). A Brief Measure of Social Support: Practical and Theoretical Implications. Journal of Social and Personal Relationships.

Scalon, C. A., Arick, C., & Phelps, N. (1981). Participation in the Development of the IEP: Parents' Perspective. Exceptional Children, 47(5), 373-376.

Schilling, R. F., Kirkham, M. A., Snow, W. H., &

Schinke, S. P. (1986). Single Mothers with Handicapped Children: Different from their Married Counterparts? Family Relations, 35, 69-77.

Schulz, J. B. (1982). A parent views parent participation. Exceptional Education Quarterly, August, 17-22.

Segal, M. M. (1985). An Interview Study with Mothers of Handicapped Children To Identify Both Positive and Negative Experience That Influence Their Ability To Cope. (ERIC Document Reproduction Service No. ED 271 907).

Shevin, M. (1983) Meaningful Parent Involvement in Longrange Educational Planning for Disabled Children. Education and Training of the Mentally Retarded, 18(2), 17-20.

Suelzle, M., & Keenan, V. (1981). Changes in Family Support Networks over the Life Cycle of Mentally Retarded Persons. American Journal of Mental Deficiency, 86(3), 267-274.

Thoits, P. A. (1986). Social Support as Coping Assistance. Journal of Consulting and Clinical Psychology, 54(4), pp. 416-423.

Turnbull, A. P. (1978). Moving from being a professional to being a parent: A startling experience. In A. P. Turnbull & H. R. Turnbull (Eds.), Parents Speak Out: Views from the other side of the two-way mirror. Columbus, OH: Charles Merrill.

Turnbull, A. P., & Turnbull, H. R. (1982). Parent Involvement in the Education of Handicapped Children: A Critique. Mental Retardation, 20(3), 115-122.

Turnbull, H. R., Turnbull, A. P., & Wheat, M. J. (1982). Assumptions about parental participation: a legislative histroy. Exceptional Education Quarterly, 3(2), 1-8.

Upshur, C. C. (1982). Respite Care for Mentally Retarded and Other Disabled Populations: Program Models and Family Needs. Mental Retardation, 20 (1), 2-6.

U.S. Bureau of the Census (1984). Statistical Abstracts of the United States (101st ed.). Washington, D. C.: Department of Commerce, 1980.

Vincent, L. J., & Salisbury, C. L. (1988). Changing Economic and Social Influences on Family Involvement. Topics In Early Childhood Special Education, 8(1), 48-59.

Waisbren, S. E. (1980). Parents' Reactions after the Birth of a Developmentally Disabled Child.

American Journal of Mental Deficiency, 84(4), 345-351.

Weinraub, M., & Wolf, B. M. (1983). Effects of Stress and Social Supports on Mother-Child Interactions in Single- and Two-Parent Families. Child Development, 54, 1297-1311.

Wiegerink, R., Hocutt, A., Posante-Loro, R., & Bristol, M. (1980). Parent Involvement in Early Education Programs for Handicapped Children. In J. J. Gallagher (Ed), New Directions for Exceptional Children. (pp. 67-85).

Wiegerink, R., Posante-Loro, R., & Bristol, M. (1978). Parent Involvement in Programs for Handicapped: Parent Involvement Survey Form. Chapel Hill: Frank Porter Graham Child Development Center, University of North Carolina.

Wikler, L. Wasow, M., & Hatfield, E. (1981). Chronic Sorrow Revisited: Parents' vs. Professionals' Depiction of the Adjustment of Parents of Mentally Retarded Retarded Children. American Journal of Orthopsychiatry, 51(1), 63-70.

Wikler, L. (1986). Periodic Stress of Families of

Older Mentally Retarded Children: An Explanatory Study. American Journal of Mental Deficiency, 90(6), 703-706.

Wilton, K., & Renaut, J. (1986). Stress Levels In Families With Intellectually Handicapped Preschool Children. Journal of Mental Deficiency Research, 30, 163-169.

Winton, P. (1986). Effective Strategies for Involving Families in Intervention Efforts. Focus on Exceptional Children, 19(2), 1-11.

Winton, P., & Turnbull, A. P. (1981) Parent Involvement as viewed by parents. Topics of Early Childhood Special Education, 1(3), 11-19.

Wishart, M. C., Bidder, R. T., Gray, O. P. (1981). Parents' report of family life with a developmentally delayed child. Child: care, health and development, 7, 267-279.

Wolf, J. S. (1982). Parents as Partners in Exceptional Education. Theory into Practice, 21 (2), pp. 77-81.

Yoshida, R. K., Fenton, K. S., Kaufman, M. J., & Maxwell, J. P. (1978). Parental Involvement in the Special Education Planning Process: The School's Perspective. Exceptional Children, 44(7), 531-533.

APPENDIX A

DEMOGRAPHIC DATA SHEET

PARENT
Sex: Female ___ Male ___

Education: Last year of schooling completed:
Less H.S. ___
H.S. ___
1-2 yr college ___
4 yr college ___
Grad. school ___

Employment:
Professional: ___
Technical/trades: ___
Sales: ___
Clerical: ___
Paraprofessional/Volunteer: ___
Domestics: ___
Homemaker: ___
Unemployed: ___

CHILD Age (Yrs.) _____ Sex: Female ___ Male ___
Educational Program: Special School ___
Self-contained Classroom ___
Resource Room/Regular Classroom ___
Regular Classroom ___
Other: ____________________________

Transition Stage:
Mark only the stage or stages that apply to your situation
-Diagnosis (official news of handicap from specialist) ___
-Child should have begun walking (12-15 months) ___
-Child should have begun talking (24-30 months) ___
-Younger brother or sister overtakes the handicapped child's abilities ___
-Serious discussion of placement of your child outside your home __
-Beginning of your child's attendance of a public school ___
-Management of a crises (behavior problems, seizures, health problems, etc.) unique to your child ___
-Onset of puberty ____
-Child's 21st birthday is coming up; concern about the child's futu after leaving High School ___
-Serious discussion about care and guardianship when parents die __
-No transition stage ___

Severity of Disability:

Please assign <u>one number to each of the following areas</u> indicating your child's degree of functioning in this area. **Use the code to your right.**

Vision________________

Hearing_______________

Physical Abilities____

Social Social Abilities______

Language______________

Mental Abilities______

Behavior______________

0 100 % functional

1 75-90 % functional: mild problems

2 50-74 % functional: moderate problems

3 25-49 % functional: severe problems

4 0-24 % functional: profound problems

<u>FAMILY</u>

Marital Status: Single____________ Separated__________ Married_________

Divorced___________ Widowed___________

Family Income:____________ per year.

APPENDIX B

The Questionnaire On Resources And Stress-Friedrich

Dear Parent:

This questionnaire deals with feelings (your feelings) about the exceptional child in your family. There are many blanks on the questionnaire. Your child's name is to be seen filled in on each blank. Give your honest feeling and opinion. Please **circle or cross** True (T) o False (F). Answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feels or does **most** of the tim Sometimes the questions refers to a problem your family does not have. Nevertheless, they can be answered True or False, even then. Remember to answer all of the questions. If you have any concerns, don't hesitate t ask.

1. __________ doesn't communicate with others of his/her age. T F
2. Other members of the famlily have to do without things because of __________. T F
3. Our family agrees on important matters. T F
4. I worry about what will happen to __________ when I can no longer take care of him/her. T F
5. The constant demands of care for __________ limit growth and development of someone else in our family. T F
6. __________ is limited in the kind of work he/she can do to make a living. T F
7. I have accepted the fact that __________ might have to live out his/her life in some special setting (e.g. instituion or group home). T F
8. __________ can feed himself/herself. T F
9. I have given up things I have really wanted to do in order to care for __________. T F
10. __________ is able to fit into the family social group. T F
11. Sometimes I avoid taking __________out in public. T F
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress. T F
13. It bothers me that __________ will always be this way. T F
14. I feel these whenever I take __________ out in public. T F
15. I can go visit with friends whenever I want. T F
16. Taking __________ on a vacation spoils pleasure for the whole family. T F
17. __________ knows his/her own address. T F
18. The family dows as many things together now as we ever did. T F
19. __________ is aware who he/she is. T F
20. I get upset with the way my life is going. T F
21. Sometimes I feel very embarassed because of __________. T F
22. __________ doesn't do as much as he/she should be able to do. T F
23. It is difficult to communicate with __________ because he/she has difficulty understanding what is being said to him/her. T F

24. There are many places where we can enjoy ourselves as a family when __________ comes along. T F
25. __________ is over-protected. T F
26. __________ is able to take part in games or sports. T F
27. __________ has too much time on his/her hands. T F
28. I am disappointed that __________ does not lead a normal life. T F
29. Time drags for __________, especially free time. T F
30. __________ can't pay attention very long. T F
31. It is easy for me to relax. T F
32. I worry about what will be done with __________ when he/she gets older. T F
33. I get almost too tired to enjoy myself. T F
34. One of the things I appreciate about __________ is his/her confidence. T F
35. There is a lot of anger and resentment in our family. T F
36. __________ is able to go to the bathroom alone. T F
37. __________ cannot remember what he/she says from one moment to the next. T F
38. __________ can ride a bus. T F
39. It is easy to communicate with __________. T F
40. The constant demands to care for __________ limit my growth and development. T F
41. __________ accepts himself/herself as a person. T F
42. I feel sad when I think of __________. T F
43. I often worry about what will happen to __________ when I no longer can take care of him/her. T F
44. People can't understand what __________ tries to say. T F
45. Caring for __________ puts a strain on me. T F
46. Members of our family get to do the same kinds of things other families do. T F
47. __________ will always be a problem to us. T F
48. __________ is able to express his/her feelings to others. T F
49. __________ has to use a bedpan or a diaper. T F
50. I rarely feel blue. T F
51. I am worried much of the time. T F
52. __________ can walk without help. T F

THANK YOU MUCH FOR YOUR COOPERATION!

With permission taken from Friedrich, W. N. et al. (1983).

APPENDIX C

SOCIAL SUPPORT QUESTIONNAIRE SHORT-REVISED (SSQSR)

Dear Parent:

The following questions ask about people in your environment who provide you with help or support. Each question asks two parts. For th first part, list all the people you know, excluding yourself, whom you c count on for help or support in the manner described. Give the persons' initials (you may use made-up initials; in case you list the same person twice, please use the same initial); their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how satisfied you are with the overall support you have.

If you have had no support for a question, check the words "No one, but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all the questions as best you can. All your response will be kept confidential.

EXAMPLE

Who do you know whom you can trust with information that could get you i trouble?

__ No one	1) T.N.	(brother)	4) A.N.	(father)	7)	
	2) L.M.	(friend)	5) L.S.	(employer)	8)	
	3) R.S.	(friend)	6)		9)	

How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfi

---

1. Who can you really count on to be dependable when you need help?

__ No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

2. How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfi

3. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

__ No one

1)
2)
3)
4)
5)
6)
7)
8)
9)

4. How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfi

5. Who accepts you totally, including both your worst and your best points?

__ No one

1)
2)
3)
4)
5)
6)
7)
8)
9)

6. How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfi

7. Whom can you really count on to care about you, regardless of what is happening to you?

__ No one

1)
2)
3)
4)
5)
6)
7)
8)
9)

8. How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfi

9. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

__ No one

1)
2)
3)
4)
5)
6)
7)
8)
9)

10. How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfi

11. Whom can you count on to console you when you are very upset?

__ No one
1)
2)
3)
4)
5)
6)
7)
8)
9)

12. How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfi

THANK YOU FOR YOUR COOPERATION!

With permission taken from Sarason, I. E. et al. (1987).

APPENDIX D

Parent/Family Involvement Index

Dear Parent:

This questionnaire asks for your participation in several activities related to your child's education. **The** left column asks how you are currently involved **(actual parent participation)**; the right column asks the degree you would like to be involved **(needed parent participation)**.

How to complete the Index:

You can choose among four (4) possible responses to the items in the index:

Yes = the item is true for you;

No = the item is not true for you;

N.A. = (not applicable), the item does not apply to you or your child's school situation; and,

D.K. = you don't know whether the item is true for you.

Please mark the one response that is most true for you!

If you are a **mother** please answer only the line marked with **M.**

If you are a **father** please answer only the line marked with **F.**

An example of a mother's response to an item would be:

Actual Parent Participation						**Needed Parent Participation**			
Yes	No	N.A.	D.K.			Yes	No	N.A.	D.K.
x				M	(a) Parent has met teacher or aide at least once	x			
				F					

In this case, the mother has met the teacher or aide. The mother's wish is the same as it actually is.

If you have questions, don't hesitate to ask.

THANK YOU MUCH FOR YOUR COOPERATION!

P./F.I.I. cont'd

Parent/Family Involvement Index

M = Mother

F = Father

Actual Parent Participation						**Needed Parent Participation**			
Yes	No	N.A.	D.K.		1. Contact with Teacher	Yes	No	N.A.	D.K.
___	___	___	___	M	(a) Parent has met teacher or teacher's aide at least once.	___	___	___	___
___	___	___	___	F		___	___	___	___
Yes	No	N.A.	D.K.		2. Participation in Special Education Process	Yes	No	N.A.	D.K.
___	___	___	___	M	(a) Parent completed screening/ assessment device concerning child upon request by teacher	___	___	___	___
___	___	___	___	F		___	___	___	___
Yes	No	N.A.	D.K.		3. Transportation	Yes	No	N.A.	D.K.
___	___	___	___	M	(a) Parent has transported child from home to bus stop.	___	___	___	___
___	___	___	___	F		___	___	___	___
Yes	No	N.A.	D.K.		4. Observations at School	Yes	No	N.A.	D.K.
___	___	___	___	M	(a) Parent has observed child in classroom activity at least once.	___	___	___	___
___	___	___	___	F		___	___	___	___
Yes	No	N.A.	D.K.		5. Educational Activities at Home	Yes	No	N.A.	D.K.
___	___	___	___	M	(a) Parent has allowed teacher, teacher's aide, or school social worker to visit home on at least on occasion.	___	___	___	___
___	___	___	___	F		___	___	___	___
Yes	No	N.A.	D.K.		6. Attending Parent Education/ Consultation Meetings	Yes	No	N.A.	D.K.
___	___	___	___	M	(a) Parent has attended at least one parent group meeting designed for training educational techniques, child care, or behavior management skills.	___	___	___	___
___	___	___	___	F		___	___	___	___

Yes	No	N.A.	D.K.		7.	Classroom Volunteering	Yes	No	N.A.	D.K.
___	___	___	___	M		(a) Parent has volunteered to provide services to school, outside of the classroom	___	___	___	___

M = Mother
F = Father

Yes	No	N.A.	D.K.		7.	Classroom Volunteering	Yes	No	N.A.	D.K.
___	___	___	___	M		(a) Parent has volunteered to provide services to school, outside of the classroom (nurse's aide, office help, school yard maintenance, crossing guard).	___	___	___	___
___	___	___	___	F			___	___	___	___
Yes	No	N.A.	D.K.		8.	Parent-Parent Contact and Support	Yes	No	N.A.	D.K.
___	___	___	___	M		(a) Parent has called, or spoken to in person, other parents concerning classroom related issues.	___	___	___	___
___	___	___	___	F			___	___	___	___
Yes	No	N.A.	D.K.		9.	Involvement with Administration	Yes	No	N.A.	D.K.
___	___	___	___	M		(a) Parent has sought information concerning administration or policy making procedures of the classroom or school.	___	___	___	___
___	___	___	___	F			___	___	___	___
Yes	No	N.A.	D.K.		10.	Involvement in Fund Raising Activities	Yes	No	N.A.	D.K.
___	___	___	___	M		(a) Parent has suggested fund raising activites which could be conducted.	___	___	___	___
___	___	___	___	F			___	___	___	___
Yes	No	N.A.	D.K.		11.	Involvement in Advocacy Groups	Yes	No	N.A.	D.K.
___	___	___	___	M		(a) Parent has actively sought information about advocacy groups (e.g., GOARC, ACLD, CEC, etc.).	___	___	___	___
___	___	___	___	F			___	___	___	___
Yes	No	N.A.	D.K.		12.	Dissemminating Information	Yes	No	N.A.	D.K.
___	___	___	___	M		(a) Parent has referred other parent (s) to programs serving special children.	___	___	___	___
___	___	___	___	F			___	___	___	___

13. <u>Overall</u>, I would consider my **actual parent's participation** in our program as: (Place an X on one number).

Mother	1	2	3	4	5	6
Father	1	2	3	4	5	6

Not at all involved   Somewhat involved   Extremely involved

14. <u>Overall</u>, I would consider my **needed parent's participation** in our program as: (Place an X on one number).

Mother	1	2	3	4	5	6
Father	1	2	3	4	5	6

Not at all involved   Somewhat involved   Extremely involved

THANK YOU!

With permission taken and adapted from Cone et al., (1985). In respect to the Copyright on P./F.I.I. only one item per involvement area is listed.

APPENDIX E

University of
Nebraska
at Omaha

College of Education
Department of Counseling (402) 554-2727
and Special Education (402) 554-2201
Omaha, Nebraska 68182-0167

AN INVITATION

Ralf W. Schlosser
745 N. 58th Street
Omaha, NE 68132
10 September, 1987
(402) 553-3265

Dear Parents:

I am a Graduate Student working on a Master's Degree in Special Education at the University of Nebraska at Omaha (UNO). I am in the process of writing a thesis reflecting my major interest: parent participation in special education.

You have been selected from 6000 parents of students involved in special education of Omaha Public Schools (OPS) for this research. The study deals with the stress of being a parent of an exceptional child; social support systems for families; and, participation in your child's educational program.

OPS has granted permission to implement this study. Your personal input is of vital importance to assist teachers to improve education as well as the quality of your participation in your child's program.

I will be hosting meetings during which I will ask you to complete three questionnaires. The meetings will take about 75 minutes. Your name is not required; your confidentiality is assured.

If you are willing to cooperate in this project, please mark on the enclosed pre-stamped postcard the date and location most convenient to you and return it to me. If you would like to participate but cannot attend a meeting, mark the second option and fill your address in the box so that I can mail the questionnaires.

For your enjoyment I will treat German chocolate cake and coffee. I will be available for questions or concerns you might have during the time you will be completing the questionnaires.

I look forward to meeting with you. I see this as an opportunity to help teachers improve education for special needs children by gaining a greater understanding of parental stressors and participation.

Thank you very much for your effort and cooperation.

Yours sincerely,

Ralf W. Schlosser

Ralf W. Schlosser
Graduate Student
Special Education

Sandra Squires

Sandra Squires, Ed.D.
Chairperson, Counseling
and Special Education

RWS/kb
cc: Larry Heck

APPENDIX F

YOUR HELP IS REQUESTED

RALF W. SCHLOSSER
745 North 58th Street
Omaha, NE 68132
1 October, 1987
402/553-3265

Dear Parents:

A study on **Parent Participation** is being conducted at UNO through a graduate thesis project in the Department of Special Education.

Three (3) areas of emphasis included in this study are as follows: parents' particiaption with their child at school, at home, and in the community; parent stress; and, social support. If you would be interest in becoming a part of the project, please return this form for the questionnaires to be mailed to you.

What's involved? Three (3) sets of questions that will take about minutes of your time. A stamped return envelop will be provided.

Your personal participation would be greatly appreciated.

Sincerely,

Ralf W. Schlosser	Sandra K. Squires, Ed.D.
Graduate Student	Chairperson, Department of
Special Education	Counseling and Special Education

__ Yes, I/We want **two** sets of questionnaires for a two-parent family.

__ Yes, I want **one** set of questionnaires for a one-parent family.

__ And, I would like to be invited to the Seminar on Parent Parent Participation in Special Education scheduled for the evening of Thursday, August 4, 1988. My home telephone ________________.

Name ____

Address ____

City __________________________,NE ZIP ______________

Return to: Ralf W. Schlosser
745 North 58th Street
Omaha, NE 68132

APPENDIX G

Table 11

Internal Consistency (KR-21) Values for the Scales of the Parent/Family Involvement Index

Scale	N Items	KR-21 Mothers	KR-21 Fathers
Contact with Teacher	6	.45	.80
Participation in Special Education Process	5	.74	.89
Transportation	4	.78	.80
Observations at School	4	.72	.44
Educational Activities at Home	6	.79	.92
Attendance at Parent Ed./ Consult. Meetings	5	.93	.87
Classroom Volunteering	6	.83	.73
Parent-Parent Contact and Support	7	.98	.95
Involvement with Admin.	4	.73	.87
Involvement in Fund Raising	5	.86	.65
Involvement in Advocacy	5	.97	.96
Disseminating Information	6	.95	.94
Total Involvement Score	63	.94	.94

Cone, J. D., DeLawyer, D. D., and Wolfe, V. V. (1985). Assessing Parent Participation in Special Education Programs: The Parent/Family Involveme Index. West Virginia University. P. 21.

APPENDIX H

Table 12

Frequency/Percentage, Range and Mean of Demographic Information.

Demographic Variables		N = %	Ma
	Parent Variables		
Sex: Males		28	
Females		72	
Education: Less H. S.		5	
	H. S.		29
	1-2 yr. college		28
	4 yr. college		16
	Graduate School		22
Employment: Professional		41	
	Technical/Trades		12
	Sales		8
	Clerical		9
	Paraprofessional		4
	Domestics		3
	Homemaker		20
	Unemployed		3
	Child Variables		
Age (in years):			11.1
Educational Program:			
Special School		9	
Self-Contained Classroom		32	

Resource Room/Regular Classroom	33	
Regular Classroom	10	
Others	16	
Family Variables		
Family Status: Single	7	
Married	80	
Separated	0	
Divorced	1	
Widowed	12	
Family Income: Less than $ 10,000	8	$ 27,319
$ 11,000 to 20,000	20	
$ 21,000 to 30,000	19	
$ 31,000 to 40,000	18	
$ 41,000 to 50,000	21	
More than $ 51,000	3	

---

a The Mean is given for variables where it is meaningful.

APPENDIX I

Table 13
Parental Perception of Severity of Disability: Functional Areas Code

No. of Child	VIS	HEAR	PHYS	SOCIAL	LAN	MENT	BEHAV	Total
001	0	0	0	0	0	3	3	6
002	0	0	1	3	0	2	4	10
003	0	3	0	3	0	0	3	9
004	0	2	0	3	3	2	3	13
005	0	2	0	1	1	0	0	4
006	0	0	0	0	0	0	0	0
007	1	2	0	2	2	2	2	11
008	1	0	3	1	1	2	1	9
009	0	1	2	2	0	1	2	8
010	0	0	3	3	3	2	1	12
011	0	1	2	2	0	0	2	7
012	1	0	3	1	3	1	0	9
013	0	2	0	3	0	1	4	10
014	0	0	0	2	0	3	2	7
015	0	0	2	3	4	3	1	13
016	0	0	1	3	4	2	1	11
017	0	0	0	2	4	3	0	9
018	1	3	1	2	2	2	0	11
019	1	2	0	0	0	3	1	7
020	1	3	2	3	4	3	1	17
021	0	0	0	0	3	0	0	3
022	1	0	0	1	0	0	1	3
023	0	0	2	2	4	3	2	13
024	0	0	3	2	4	3	2	14
025	0	0	0	0	1	0	0	1
026	0	0	0	0	0	0	0	0
027	0	0	0	0	2	0	0	2
028	0	0	1	1	1	1	1	5
029	0	0	0	0	0	0	2	2
030	0	0	0	0	0	1	0	1
031	0	0	1	1	1	0	1	4
032	0	1	2	2	1	2	2	10
033	0	1	0	0	2	0	1	4
034	0	3	2	2	2	2	2	13
035	0	2	2	2	2	2	2	12
036	0	2	2	2	1	3	4	14
037	0	0	1	2	2	2	2	9
038	0	0	0	4	4	4	4	16
039	0	1	1	4	4	4	4	18
040	2	1	0	2	1	2	2	10
041	4	0	1	3	3	3	3	17
042	1	0	0	2	1	2	2	8
043	0	0	1	1	1	1	1	5
044	2	0	0	0	0	0	0	2
045	2	0	0	0	0	0	0	2
046	0	0	0	0	2	0	0	2

047	0	0	0	2	1	1	0	4
048	0	0	0	0	0	2	1	3
049	0	4	0	0	1	0	0	5
050	0	4	0	1	1	0	1	7
051	0	0	2	0	1	1	0	4
052	0	0	2	0	1	1	0	4
053	0	0	1	2	2	2	1	8
054	0	0	2	2	2	2	2	10
055	1	0	1	1	2	2	2	9
056	1	0	1	1	2	2	2	9
057	0	0	1	2	2	2	2	9
058	0	3	0	1	2	0	0	6
059	0	4	0	2	3	0	0	9
060	0	0	1	2	0	0	1	4
061	1	1	0	1	0	0	3	6
062	2	0	3	1	2	2	0	10
063	0	0	3	1	3	2	1	10
064	0	0	1	2	0	2	4	9
065	3	0	0	1	0	0	0	4
066	0	2	0	0	2	0	0	4
067	0	2	0	0	2	0	0	4
068	2	0	4	1	1	2	0	10
069	0	0	1	1	2	3	1	8
070	0	0	0	0	1	2	0	3
071	0	0	1	2	4	3	2	12
072	0	0	0	0	1	1	0	2
073	0	0	3	2	2	1	0	8
074	0	0	2	1	1	1	0	5
075	0	1	0	0	0	0	2	3
076	1	1	4	4	4	2	1	17
077	3	1	3	4	2	3	4	20
078	0	0	3	1	1	1	2	8
079	0	0	3	0	0	0	2	5
080	1	0	2	3	4	2	1	13
081	0	1	0	0	0	0	0	1
082	0	0	0	1	2	0	0	3
083	0	0	0	0	0	0	0	0
084	1	0	2	3	1	2	3	12
085	0	0	0	0	1	0	0	1
086	0	0	1	0	0	0	0	1
087	0	0	1	3	1	2	1	8
088	0	0	1	0	0	0	0	1
089	2	0	3	2	2	1	2	12
090	0	2	0	3	1	3	3	12
091	1	0	1	1	1	0	1	5
092	0	0	1	1	0	0	1	3
093	0	0	0	1	1	0	1	3

094	1	0	0	0	2	2	0	5
095	0	1	2	2	1	0	1	7
096	3	0	1	0	0	1	0	5
097	1	0	1	1	2	0	0	5
098	0	2	0	2	1	1	2	8
099	1	1	1	3	1	1	1	9
100	0	0	0	1	0	0	2	3
TOTAL	43	62	98	137	134	125	122	721

Evaluation Code:

0 = No significant problem
1 = 75 - 90 % functional
2 = 50 - 74 % functional
3 = 25 - 49 % functional
4 = 0 - 24 % functional

APPENDIX J

Table 14

Correlation Matrix: Concurrent Validity of the QRSF

Factor	1	2	3	4	5	6
1. Parent and Family Problems						
2. Pessimism	.35*					
3. Child Characteristics	.20	.22				
4. Physical Incapacitation	.23	.51**	.46**			
5. Beck Depression Inventory	.41**	.39*	.17	.06		
6. Social Desirability Scale	-.38*	-.13	.09	.03	-.25	
7. Problem Checklist	.21	.24	.43**	.67**	.19	.01

* $p < .05$, Spearman rho.
** $p < .01$.

(Friedrich, Greenberg, Crnic, 1983, p. 46)