Parents of Children with Severe Disabilities: Parental Stress, Depression, and the Marital Relationship

Melinda W. Christensen
Utah State University

Follow this and additional works at: https://digitalcommons.usu.edu/gradreports

Part of the Psychology Commons

Recommended Citation
Christensen, Melinda W., "Parents of Children with Severe Disabilities: Parental Stress, Depression, and the Marital Relationship" (2002). All Graduate Plan B and other Reports. 980.
https://digitalcommons.usu.edu/gradreports/980

This Report is brought to you for free and open access by the Graduate Studies at DigitalCommons@USU. It has been accepted for inclusion in All Graduate Plan B and other Reports by an authorized administrator of DigitalCommons@USU. For more information, please contact digitalcommons@usu.edu.
PARENTS OF CHILDREN WITH SEVERE DISABILITIES:
PARENTAL STRESS, DEPRESSION, AND THE MARITAL RELATIONSHIP

by

Melinda W. Christensen

A plan B paper submitted in partial fulfillment
of the requirements for the degree of

MASTER OF SCIENCE

in

School Psychology

Approved:

UTAH STATE UNIVERSITY
Logan, Utah

2002
Abstract

This paper provides an overview of parental stress and depression in families with children diagnosed with severe cognitive disabilities. Previous research on parents with children with disabilities was reviewed. Studies were selected from peer-reviewed journal articles that specifically included children with an IQ below 70 or a noted cognitive impairment of a severe degree. Children in the study had to be living at home and below the age of 21. Significant levels of stress and depression were not found consistently in the studies reviewed. Parents of children with disabilities did report levels of stress and depression above the control groups in the studies or normative samples when available for comparison. The review also looked at the relationship between having a child with a severe disability and the parents' martial relationship. Little support was found in the articles reviewed for the hypothesis that having a child with a severe disability results in dysfunction in the marital relationship. The significance of social support, both informally and formally, was noted in several articles reviewed. The need for continued and additional support and intervention for families is discussed. Conclusions and recommendations for future research are presented as well as implications for mental health professionals and school practitioners working with families with children with severe disabilities.
### CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Purpose of Current Paper</td>
<td>3</td>
</tr>
<tr>
<td>Inclusion and Exclusion Criteria for Studies Reviewed</td>
<td>4</td>
</tr>
<tr>
<td>Review of Related Research Findings</td>
<td>5</td>
</tr>
<tr>
<td>Review of Parental Stress Studies</td>
<td>12</td>
</tr>
<tr>
<td>Review of Parental Depression Studies</td>
<td>29</td>
</tr>
<tr>
<td>Review of Marital Relationship Studies</td>
<td>35</td>
</tr>
<tr>
<td>Conclusion</td>
<td>42</td>
</tr>
<tr>
<td>Implications for School Psychologists and Other School Practitioners</td>
<td>49</td>
</tr>
<tr>
<td>References</td>
<td>55</td>
</tr>
</tbody>
</table>
Introduction

Researchers and clinicians are increasingly interested in the study of children with disabilities. This interest has come about in part because of advances in medical care and technology, which have resulted in an increase in the number of children living with physical and/or developmental delays. With the increase in medical care and technology has come increased support for families. The education system has also become more supportive of families with the passage of Public Law 94-142 that provides for education of all children with disabilities. As the support has increased through these and other public programs, parents are more able and willing to care for their child with a disability in their home as opposed to an institution or other professional care setting. With these changes there is an emerging awareness of the need to understand the processes governing the development of these children. Children with delays differ in important ways from typically developing children who have been the focus of most developmental and psychological research.

Recently, researchers have attended to the impact that a child with a disability has on family members and the role social support plays in mediating the stress of having a child with a disability in the family (Kazak & Marvin, 1984; Seligman, 1985). The impact of the child with a disability on the spousal relationship has been a particular focus of several studies (e.g., Friedrich & Boriskin 1976; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). Others have focused on the effect having a child with a disability has on parental stress and depression (e.g., Beckman, 1991; Dyson, 1997; Frey, Greenberg, Fewell, 1989; Krauss, 1993; Speltz, Armsden, & Clarren, 1990). It is important to review these parental factors, as it is believed that the impact of the
disability on a marriage and parents, in turn, strongly effects the psychosocial adaptation of the child with a disability. However, there has been little agreement on the extent and nature of the impact that having a child with a disability has on the parents. A review conducted in 1983 by Crnic, Freidrich, and Greenberg looked at the adaptation of families with children with mental retardation. They found that the individual parents and siblings of children with mental retardation, as well as the families as a whole, were at-risk for numerous difficulties in comparison to families who did not have a child with mental retardation. The researchers also reported that inconsistent and contradictory research findings were common, due primarily to variations in methodological adequacy, inappropriate control groups, small and poorly defined samples, and the use of measures of greatly uneven quality. Crnic et al. determined that current research at the time had numerous shortcomings and they stated a need for more research to better understand the family adaptation.

The present literature review will examine the association between having a child with a severe disability and the parents’ marital relations, parental stress, and parental depression. For the purpose of this paper, a severe disability is defined as an individual having an IQ score below 70 or identification within the article reviewed that the child has been diagnosed as mentally retarded or has been given a diagnosis that includes mental deficiency. This criteria allows for but does not require the inclusion of children with physical and/or other co-morbid disabilities. The main questions of interest in this review are: 1) What is the association between having child with a severe disability and the amount of stress experienced in parenting that child? 2) What is the association between having child with a severe disability and the severity of depression experienced
by parents? and 3) What is the association between having child with a severe disability and the quality of the parents’ marital relationship?

Another important aspect to parental functioning and family adaptation is support, both formal and informal. This topic will be discussed briefly in a review of related research. Support (e.g. support from the school, agencies, family) is also discussed in terms of predictors/correlates of stress, depression, and marital problems in the article summaries and at the conclusion of this paper. Support was not included as a main point of investigation in this review because of its broad scope. When looking at support and what kinds of support can effect parental depression, stress, and the marital relationship the range could include support from the school, state services, tax breaks, friends, relatives, medical professionals, community, literature, parent training, support groups, and/or internet site chat rooms.

Purpose of Current Paper

To determine the relationship between having a child with a severe cognitive disability and the psychological status of the child’s parents, this paper will examine the research that has been completed on parental stress, depression, and marital relations in parents with children with severe cognitive disabilities. The following section defines the method used to select the studies included in this paper, after which research articles will be described. Following the description of the studies and the summary of their individual results, a combined summary will examine collective outcomes for all the variables. Concluding the paper will be a summary of the review results and implications of the research for practicing school psychologists and other school practitioners.
Inclusion and Exclusion Criteria for Studies Reviewed

A computer search of the PsycINFO and Educational Resources Information Center (ERIC) databases were employed to locate relevant articles for review. Keywords for the search included, but were not limited to, descriptors such as disability, severe disability, mental retardation, parent, parental stress, parental depression, parental satisfaction, and spousal support. Additional articles were gathered from references provided within the primary sources.

Inclusion Criteria

In order to be included in this review, articles had to be empirical studies, published in a peer-reviewed journal. The literature review is focused on parents of children with severe cognitive disabilities and the relationship to the level of parental stress, depression, and marital difficulties. Therefore, it was essential for articles to focus on parental stress, marital relationship, and/or depression and include children with a severe cognitive disability. For the purposes of this paper, a severe cognitive disability was defined as having an IQ of 70 or below. This includes individuals who are mentally retarded, intellectually disabled, or have been diagnosed with Down syndrome. Children in the studies reviewed had to live with at least one parent and not in an institution or a professional care facility. The reason for this is that the level of parental stress, depression, and the marital relationship would likely be significantly different in families in which the child with a disability is living in their home as opposed to living in a care facility. Also, more today than in decades ago, children with disabilities are living with their biological families. This trend has been one of the reasons for additional research in this area. The last inclusion criterion is that the studies had to include children under age
A main purpose of this review is to look at the implications from the research for school practitioners. Children with severe disabilities receive early intervention and education from schools until the age of 21. Included articles were confined to those available through Utah State University’s libraries or Interlibrary Loan during June 2001 through February 2002.

Exclusion Criteria

Studies were excluded from the review of literature if they only looked at children with disabilities who were institutionalized or placed in another home environment besides that of their parents. Articles were also excluded if they were dissertations, presentations, and/or unpublished works. And finally, research articles that looked at parental stress, martial relations, or depression in parents of children with severe disabilities children but did not present empirical data were excluded from the review.

Review of Related Research Findings

Several research studies have been conducted pertaining to this current review which do not meet the inclusion criteria to be formally reviewed. However, they provide some important information and findings that should be noted and considered when drawing conclusions about stress, depression, and the marital relationship in parents of children with severe cognitive impairments. The following related articles were found during concurrent searches of the literature to find articles pertaining to the inclusion criteria and relating to the topic of this review. Articles were included as related articles if they included children with disabilities but did not meet all of the other inclusion criteria. For example, several studies did not meet the inclusion criteria for the formal review because they included children with disabilities other than a severe cognitive
impairment and the researchers did not report findings for children with severe
disabilities separately (Dyson, 1997; Frey, Greenberg, & Fewell, 1989; Krauss, 1993;
Young & Roopnarine, 1994). Other studies reviewed in this section identified that the
children in the study had a disability but did not specify what disability (Hirst, 1991) or
did not identify the severity of the disability (Willoughby & Glidden, 1995). Kazak
(1987) was the only study reviewed here that was excluded from the formal review for
having a sample of children with disabilities who were institutionalized instead of living
at home. Several of the related research articles did not include any children with severe
disabilities but did look at stress and depression in parents with children with other
disabilities or health problems (Dyson, 1997; Krauss, 1993; Willoughby & Glidden,
1995). These latter articles are not covered as extensively as those pertaining more to
children with severe disabilities but are covered briefly. Articles that examined support
programs (e.g., respite, parent training, stress management) available to families with
children with severe disabilities were also included in this section (Baker, Landen, &

The findings of these related articles have mixed results yet can be useful in
analyzing the articles included in this review. Kazak (1987) and Dyson (1997) both
found that mothers of children with disabilities had clinically significant stress levels.
Dyson (1997) also found clinically significant levels of stress for fathers. She noted that
mothers and fathers with children with disabilities experienced similar amounts of stress
and did not differ in their family functioning and social support experiences. Krauss
(1993) also reported that mothers and fathers of children with disabilities did not differ in
the amount of stress that they experienced but both reported stress levels below the
clinically significant range. Frey, Greenberg, and Fewell (1989) reported differences between mothers and fathers of children with disabilities regarding parenting stress, family adjustment, and psychological distress. For example, significant stress levels for parents of children with low communication skills and for fathers with a son with a disability were noted.

None of these related studies noted differences in marital relationship quality between parents of children with disabilities and those with children without disabilities. Hirst (1991) and Kazak (1987) found few differences in the marital relationship between parents with children with disabilities and parents of children without disabilities. Hirst found that children with disabilities were not more likely to be in a single parent home and Kazak reported no differences in marital satisfaction. Young and Roopnarine (1994) also found no significant differences existed between the parents of children with disabilities and the parents of children without disabilities on measures of parental involvement, marital stress, and functioning styles within the family.

Several of the studies identified particular factors that contributed to the levels of stress and depression experienced by parents as well as factors that effected the marital relationship. Willoughby and Glidden (1995) reported greater father participation in childcare was associated with greater marital satisfaction for both mothers and fathers of children with disabilities in their study. Dyson (1997) found the parental stress reported by parents of children with disabilities pertained specifically to parental and family problems due to the child’s special characteristics and physical limitations and the parents’ pessimism concerning the child’s future. Krauss (1993) indicated that the most powerful correlates and predictors of stress for both mothers and fathers were aspects
either of the parents themselves (e.g., their appraisal of their locus of control over their child’s development), or their perceptions of the family environment (e.g., its adaptability and cohesion), or of their social support networks (e.g., perceived helpfulness of networks). Frey et al. (1989) reported that child characteristics were not related to family adjustment overall, but communication skills of the child were strongly associated with the level of psychological distress reported by fathers (but not mothers). They also found that there was an association between adjustment and social support. The family adjustment of mothers was better if social support was higher but adjustment was not related to the amount of criticism they reported from their social support network. Father’s family adjustment was better if criticism from their social network was low but was not related to the amount of support they reported receiving. The research also indicated that mothers and fathers who rated their own coping efficacy as high, displayed better outcomes in terms of parenting stress, family adjustment, and psychological distress.

communication with other parents of children with disabilities helps many parents to better accept and care for their child with a disability. Rimmerman (1989) looked at the difference respite services made on maternal coping and stress over time and found that mothers who used home-based respite services reported less stress and increased coping resources compared to nonusers.

Several other researchers examined the need for social support and social services for parents of children with disabilities (Donavan, 1988; Kazak & Marvin, 1984; Nevin & McCubbin, 1979; Seligman, 1985; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992; Trivette & Dunst, 1992). Nevin and McCubbin (1979) found that developing family-community relationships (e.g., interpersonal relationships, involvement in religious and community activities, developing social support through families in similar stress situations) resulted in less stress for families with children with Spina Bifida. Shonkoff et al. (1992) found that the severity of the child’s disability or medical problems was related to strain in social and family relationships thus creating more stress in the parent’s life. He cited early intervention as having benefits to families, such as reduced stress. Trivette and Dunst’s (1992) research found that social support is constructive in moderating the effects of personal and family stress. They reported that social support has positive effects on maternal and family adjustment, parenting styles, parental attitudes and expectations, and child behavior and development. Kazak and Marvin (1984) found that the size of a social support group was not very important but that the quality and intensity of the group support from families experiencing similar stress was important. Donovan (1988) reported that low social support was related to high rates of stress, and the infrequent use of support services. He found that social support services
were not used in high rates and were difficult for parents to find. Seligman (1985) reported in a review of studies that social support plays an integral part in mediating stress for families with children with disabilities. He also stated that spousal support is important in alleviating strain in parents with more support leading to lower stress levels.

Other studies reviewed looked a variety of disabilities including physical disabilities (Barakat & Linney, 1992), cranial birth defects (Speltz, Armsden, & Clarren, 1990), congenital abnormalities (Gath, 1972), and Spina Bifida (Nevin & McCubbin, 1979; Tew & Laurence, 1975). Some studies looked at the child’s health (Sabbeth & Leventhal, 1984) and the effect ill health or health risks (Beckman & Pokorni, 1988; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983) had on parents. Barakat and Linney (1992) found that social support has been found to have positive effects on maternal and family adjustment. Speltz et al. (1990) reported that mothers of children with craniofacial birth defects reported higher levels of stress, lower evaluations of self-competence, and a higher degree of marital conflict when compared to mothers of children without birth defects. Gath (1972) found that two-thirds of the families in her sample with children with congenital abnormalities had either a parent with a depressive disorder or displayed obvious marital conflict. Tew and Laurence (1975) and Nevin and McCubbin (1979), while studying parents of children with Spina Bifida, found that parents of children with severe disabilities experience significantly greater stress than those of children with mild or moderate disabilities. Sabbeth and Leventhal (1984) studied chronic illnesses in children and the effect on parents. They found that divorce was not more frequent in families with children with chronic illnesses when compared to a control group although stress was more apparent in families with children with chronic
illnesses. Beckman and Pokorni (1988) and Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) researched preterm infants and the stress experienced by their families. Beckman and Pokorni (1988) found that parental stress increased with the increased caregiving needs presented with a preterm infant. Crnic et al. (1983) reported that the amount of stress families report is related to the social support they receive, particularly informal social support which includes spouses. The more support parents reported, especially from their spouse, the lower the levels of stress reported.

A few researchers focused on the relationship between having a child with a disability and stress, depression, and poor marital relationship quality (Belsky, 1984; Bradshaw & Lawton, 1978; Friedrich & Boriskin, 1976; Friedrich, 1979). Bradshaw and Lawton (1978) found that maternal parenting stress was directly related to the mother’s marital satisfaction with marital satisfaction declining as maternal parenting stress increased. Friedrich and Boriskin (1976), Friedrich (1979), and Belsky (1984) found that marital satisfaction and a good marital relationship was the best overall predictor of successful coping behavior in parents with children with disabilities.

Other researchers examined child characteristics (Beckman, 1983; Weale & Bradshaw, 1980) while others looked at family characteristics (Blancher, Nihira, & Meyers, 1987) and the outcomes of having a child with a disability, such as divorce (Cooke, Bradshaw, Lawton, & Brewer, 1986). Beckman (1983) found that the number of additional or unusual caregiving demands was highly correlated with higher levels of stress reported by mothers of infants with disabilities. Similarly, Blancher, Nihira, and Meyers (1987) reported that parents of children with disabilities are more at risk for stress because their children with disabilities often express more negative behavioral and
temperamental qualities. They found spousal support to be the greatest source of social support for mothers to counterbalance the child's characteristics and alleviate stress. Friedrich et al. (1985) found that spousal support was positively correlated with parents' psychological well-being and the quality of care they reported providing for their child. Mixed results were found when looking at divorce and parental separation, Weale and Bradshaw (1980) reported that having a child with a severe disability results in higher rates of divorce and separation than is found in parents without children with disabilities while Cooke et al. (1986) found no such differences.

The results from the majority of articles indicate children with disabilities do create a heavier burden for parents, often putting them at higher risk for stress, depression, and difficulty in their marriage. The results of this related articles review are mixed but in several studies, researchers found that social support helps parents to cope with the added stress of having a child with a disability or health problem. Formal support such as respite care, parent training, stress management, and early intervention was also found to provide beneficial results in alleviating strain on families. One of the strongest sources of support cited in several articles was spousal support. Considering the small number of articles that were included in the formal review of articles in this paper, the findings of these related articles will be helpful in making conclusions about the current research findings. In the following sections, articles that met the inclusion criteria for this review are discussed.

Review of Parental Stress Studies

Stress is a multifaceted concept and has been used to describe different phenomena. In the context of families with children with disabilities, stress may be used
to describe the physical burden of care, the emotional reaction to the child, or even the financial strains resulting from the presence of the child. Child-related stress refers to behavioral and temperamental qualities of a child (e.g., distractibility, mood, demandingness) that make it difficult for parents to fulfill their parenting roles. Parenting stress refers to dimensions of parents’ functioning (e.g., depression, sense of competence, relations with spouse) that may compromise their ability to parent effectively or may signal dysfunction of the parent-child system (Krauss, 1993). It seems likely that parents of children with disabilities could be more at risk for stress because their children with disabilities often express more negative behavioral and temperamental qualities (Blancher, Nihira, & Meyers, 1987). One or two of the child’s characteristics may not elevate parental stress levels to a clinical range but a combination of factors, including child’s temperament, family dynamics, social economic status, and so forth, may cause significant stress levels. It is important to look at the many factors that contribute to and cause stress in parents with children with disabilities when working with these families in order to know what type of support and services they are likely to benefit from the most.

In studying the impact of the child on parents, it is important to keep in mind that there are many factors that influence the nature of the parent-child and spousal relationships. The type and severity of the child’s impairment is one factor that likely mediates the effect that a child with a disability has on the parents’ stress levels. Children with severe impairments may require a great deal more care from their parents than children who are do not have disabilities or only have mild impairments. This increase in demands may influence the parents’ effectiveness in caring for their child. In addition, it may create stress in the one or both parents because the parent is preoccupied
with or exhausted from caring for the child. Research in this area has supported the idea that parents of children with severe disabilities experience significantly greater stress than those of children with mild or moderate disabilities (Nevin & McCubbin, 1979; Tew & Lawrence, 1975). In addition, the severity of the child’s disability or medical problems may be a significant predictor of negative family-level effects such as marital disintegration, marital dissatisfaction, greater role tension and psychological dysfunction among siblings, chronic and dysfunctional stress, restricted social mobility and social relationships, poor mother-child relationships (Shonkoff et al., 1992). The severity of the child’s impairment has also been related to strain in social and family relationships thus creating more stress in the parent’s life (Shonkoff et al., 1992).

Some of the common measures used to assess parental stress include the Parenting Stress Index (PSI) and the Questionnaire on Resources and Stress (QRS). The PSI was developed on the basis that the total stress a parent experiences is a function of certain salient child characteristics, parent characteristics, and situations that are directly related to the role of being a parent. The PSI is a self-report measure designed to assess the parents’ perception of characteristics of their child, the parents’ response to the child, and the parents’ own quality of life at the present time. The measure consists of 101 Likert-type questions on 14 individual scales of two major domains, child and parent. The Child Domain of the PSI is a measure of the parent’s perception of the child (subscales are demandingness, distractibility, mood, degree of reinforcement to the parent, acceptability, and adaptability). The Parent Domain of the PSI is a measure of the parent’s attachment to the child, sense of competence in the parenting role, parental depression, parent health, social isolation, restrictions in role, and relations with spouse. Responses to the PSI are
summed to yield a score for the Child Domain, Parent Domain, a Total Score, and a General Life Stress Score (single scale measuring situational or general life stress). Higher scores in any domain indicate greater stress and potentially dysfunctional parent-child relations (Abidin, 1995). Scores are considered to be clinically significant on the PSI when they are at or above the 85th percentile. Two versions of the QRS were used in the articles reviewed, neither of which has norms or cutoff scores. The Questionnaire on Resources and Stress (QRS) for Families with Chronically Ill or Handicapped Members was developed for the quantitative assessment of families' coping and adaptational responses to a disabled family member. The QRS is a measure of stress and care demands. The standard QRS form is a three factor questionnaire designed to measure 15 dimensions pertaining to families caring for family members with chronic illnesses or disabilities. These 15 subscales measure three broad categories or factors: parent problems, problems in family functioning, and problems the parent sees in the child. The QRS short form consists of five factors that evaluate a heterogeneous mix of stressors, strains, and distress associated with caring for a child with a disability. The first factor is the Parent and Family Problems scale which measures the respondents' perception of stress for themselves, other family members, and the family as a whole. The second factor is the parent Depressive Reactions scale that measures generalized feelings of unhappiness and distress. Some of the items on this scale concern more generalized feelings of unhappiness and distress and questions are not specifically related to problems associated with the child's disability. The third factor, Pessimism, is a measure of the parents' pessimism about the child's prospects of achieving self-sufficiency. The fourth and fifth factors, Child Characteristics and Physical Incapacitation, address care demands...
in terms of severity of the child's disability or problem behaviors. Specifically, the Child Characteristics factor measures perceptions of behavioral and attitudinal difficulties for the child. The Physical Incapacitation factor assesses limitations in physical abilities and self-help skills. The QRS is intended to measure sources of stress and variables that attenuate stress as well as family members' responses to stress.

Five journal articles are reviewed and analyzed to look at what researchers have found in regard to parental stress and children with an IQ below 70. Each article is summarized with its methods, procedure, and findings stated. Following the individual summary of each article, the findings and methods are compared and conclusions are made.

Beckman (1991)

Beckman (1991) compared parents of young children with and without disabilities with respect to the amount of stress parents experienced. Fifty-four mothers and 54 fathers, half with children with disabilities and half with children without disabilities were sampled. All children were from intact families and both the mother and father participated in the study. The groups were matched with respect to the child's sex and age and general demographic characteristics. Children ranged in age from 18 to 72 months. The children with disabilities included 10 with cerebral palsy, 2 with autism, 5 with multiple disabilities, 3 with genetic disorders resulting in developmental delay, and 7 with general delays of unknown origin not specifically identified in the study.

Parents in the study completed several questionnaires. To assess parental stress, parents completed the Parenting Stress Index (PSI). Mothers and fathers of children with disabilities in this study reported, on average, clinically significant scores (in the 85th
percentile or above) on the Child Domain and on the Total Score. Average scores on the Parent Domain and General Life Stress Score were below the 85th percentile for the mothers and fathers of children with disabilities. None of the parents of children without disabilities reported clinical levels (above the 85th percentile) of stress. Although clinically significant scores were not found on the Parent Domain or General Life Stress categories on the PSI for the parents of children with disabilities, their mean scores were elevated above the mean scores of the control group on all subscales. Interestingly, mothers of children with and without disabilities, reported more stress in all categories than did fathers.

Parents with children with disabilities reported lower levels of stress when higher amounts of informal support (e.g., from neighbors, friends, spouse) were reported. Mothers of children with disabilities reported higher levels of stress with increased caregiving requirements (e.g., feeding, medical care). Formal support (e.g., from professionals, agencies) was not significantly associated with stress on the Parent or Child Domains of the PSI for parents with children with disabilities.

Fisman, Wolf, and Noh (1989)

As part of a study on marital intimacy in parents of exceptional children, Fisman and associates (1989) examined self-reports of parenting stress. Depression was also evaluated and these results will be discussed in the following section of this paper.

The sample for this study consisted of parents of 124 children. Of the parents that participated in the study, 123 were mothers and 115 were fathers. All the controls were matched for sex and for mental and chronological age which researchers reported compensated for differences in children with autism where mental age lagged behind
chronological age. Control Group 1 was matched on chronological age while Control Group 2 was matched on mental age. The control groups were recruited from health clinics and doctor’s offices. The children with autism or Down syndrome were recruited from centers in which they were receiving assessment and other services. All the children in the study were living at home with at least one natural parent.

To measure stress in the parent-child relationship, parents in the study completed the Parenting Stress Index (PSI). In order to avoid potential measurement confounding between parental depression and parenting stress, the authors chose to only use the Child domain of the PSI. Mothers and fathers of children with autism reported significantly greater stress related to their child than did parents in the control groups. Parents of children with autism also reported significantly greater stress than parents of children with Down syndrome, but parents of the children with Down syndrome reported more stress than parents in both control groups. The parents of the children with autism reported clinically significant levels of stress on the PSI (above the 85th percentile). The parents of the children with Down syndrome did not report stress in the clinically significant range.

Fisman et al. reported that the stress of parenting a child with a severe disability adversely effected marital intimacy, which in turn negatively impacted the parent-child relationship. The Child Domain of the PSI measures factors that the author uses to define the parent-child relationship. Fisman used the PSI Child Domain score to measure stress in the parent-child relationship and to identify the sources of stress. The Child domain is a measure of the parent’s perception of the child (subscales are demandingness, distractibility, mood, degree of reinforcement to the parent, acceptability, and
adaptability). High levels of stress experienced in one spouse were likely to negatively effect the quality of the marital relationship. A more negative marital relationship can then lead to increased parent-child problems. When parents reported low levels of stress they reported high levels of marital intimacy and more positive parent-child relationships.

Hanson and Hanline (1990)

Hanson and Hanline (1990) conducted a longitudinal study of parental stress and adaptation. Thirty-five mothers and their children with disabilities participated in the study for over three years. Of the 35 children participating all three years, 14 were diagnosed as having Down syndrome (7 females, 7 males), 9 were diagnosed as having a hearing impairment, and twelve were diagnosed as having neurological impairments including cerebral palsy, hydrocephaly, spina bifida, and developmental delays. At the time of the initial observations, the children ranged in age from 12 to 30 months, with a mean age of 20.3 months. Subjects for this study were recruited from local early intervention programs.

As part of the study, mothers and their children were observed and interviewed 3 times over the course of the 3-year study. The Parenting Stress Index (PSI) was one of the measures parents completed at each assessment period. The scores on the PSI for the 14 children with Down syndrome showed some fluctuation over time. The Child Domain scores increased each year, reflecting an increased level of maternal stress, although the average scores never reached the clinically significant level (i.e., all scores remained below the 85th percentile). The Parent Domain scores fluctuated some over time but did not show a continuing increase, as did the Child Domain scores. As with the Child Domain scores, the average Parent Domain scores remained below the clinical level. In
comparing this research sample with the normative sample of mothers from the PSI manual, no significant differences occur with parental stress, income, marital status of mother, education of mother, or mothers' age. The normative PSI sample did include children who had been referred to clinics for diagnostic services related to behavioral or chronic health problems, such as diabetes, but did not include children diagnosed with severe disabilities.

Hanson and Hanline found that mothers' stress (both associated with child characteristics and their own experiences) as reported on the PSI was related to satisfaction with parenting and social support as measured on the Inventory of Parent Experiences (IPE). Mothers who reported higher stress reported less satisfaction with parenting and lower amounts of social support. Also, the researchers looked at differences in satisfaction with social support and parenting between mothers who were married and those who were single. Single mothers' scores on the IPE were typically lower, indicating less support. The single mothers' scores were higher on the PSI indicating higher levels of stress.

Floyd and Gallagher (1997)

Floyd and Gallagher (1997) examined parental stress, care and demands, and the use of support services for children with disabilities and behavior problems. Their study included 231 families who were a subset of a larger study looking at children with disabilities. Data were obtained from 229 mothers and 131 fathers. The sample included 144 families with parents who were married, 6 couples who were unmarried and living together, 79 single mothers and 2 single fathers who were divorced, separated, or widowed.
The families of children with mental retardation were initially recruited five years prior to this study via mailings to parents of children ages 6-18 with mild or moderate mental retardation. Of the 231 families, 112 of the families had children with mental retardation, 73 had a child who was chronically ill or physically disabled, and 46 had a child with an emotional disturbance. The 112 families with children with mental retardation were divided into two subgroups, 66 families in which the child with mental retardation did not have significant behavior problems and a subgroup of 46 families in which the child with mental retardation did have significant behavior problems.

Parents were administered several instruments in order to gather data. Stress and care demands were measured using the Questionnaire on Resources and Stress – Short Form (QRS) developed by Friedrich, Greenberg, and Crnic (1983). Although no published clinical cutoff scores were available to compare study scores with the general norm sample, comparisons can be made between study groups. The scores on all five factor scales were higher for mothers and fathers of a child with mental retardation and behavior problems than for those parents with a child with mental retardation without behavior problems except for fathers on the Child Characteristics scale. On the Child Characteristic Scale, fathers of children with mental retardation had higher scores than fathers with children who had mental retardation and behavior problems. This study also used a control group of parents who had children with behavior problems but no mental retardation. The parents in the control group had lower mean QRS scores than the parents of children with mental retardation plus behavior problems on all factor scales except for mothers on the Depressive Reaction Scale and Parent and Family Problems Scale. On these two scales, mothers in the control group scored higher than the mothers
of children with mental retardation and behavior problems. Parents with children with mental retardation but no behavior problems reported less stress than the control parents (whose children had behavior problems) except on the Pessimism and Physical Incapacitation Scales for both mothers and fathers and Child Characteristics for fathers on which they reported higher levels of stress.

Floyd and Gallagher found behavior problems to be an important determinant of parental stress and care demands. Both the presence of behavior problems and single-parent status were found to be consistent predictors of greater use of support services. They also reported that although the parents in the study reported stress and care demands across a variety of domains, they reported relatively limited use of the services available to them such as mental health services, individual and family therapy, in-home nursing, nutrition and genetic counseling, and speech and occupational therapy outside the school setting. However, the fact that the services were infrequently accessed does not mean that the services are unimportant to the families. The researchers theorized that the availability of support services, including those that are rarely used, may be an important source of stress reduction for parents. However, they did not measure this relationship in their study.

Friedrich and Friedrich (1981)

Friedrich and Friedrich (1981) studied the marital satisfaction, social support, religiosity, psychological wellbeing, and stress of parents of children with and without disabilities. Their sample consisted of 68 families, each of which included a father, a mother, and at least one child. Thirty-four families had one child with a disability who was living with them in their home. These children, who ranged in age from 2 to 16
years, were selected from a random sample of 50 families whose children had been evaluated at a regional center and who satisfied the characteristics of two parents present and a child with a disability living in the home. The sample included 8 families with children with motor difficulties, 15 children with mental retardation, and 11 whose children had a combination of motor difficulties and mental retardation. The severity of mental retardation was predominantly mild to moderate. All the parents in the disability group were asked, prior to completing the questionnaires, to nominate several families of similar size and socioeconomic status (SES) who had a child without a disability. A total of 87 families were nominated. Out of the 87 families nominated, 60 families fit the study criteria. Of the 60 selected, 34 families completed surveys and these parents constituted the control group. The groups were matched for age, family income, age of mother, and family size.

Mothers in each family completed five instruments, including the standard version of the Questionnaire on Resources and Stress, designed to measure 15 dimensions pertaining to families caring for family members with disabilities or who were chronically ill. The Psychological Well-Being Index was used as an indicator of mental health.

The mean Total Score on the QRS for mothers with children with disabilities was almost double that of the mean score of the control mothers. The results of the Psychological Well-Being Index were not as dramatic but still indicated that mothers of children with disabilities experience less psychological well-being than mothers of children without disabilities. The researchers reported that the parents of children with disabilities reported a less satisfactory marriage, less social support, and less
psychological well being than did the parents with children without disabilities. The researchers noted that because mothers of children with disabilities reported fewer psychosocial assets, as measured by the instruments in the study (e.g., marital satisfaction, religiosity, social support, psychological well being), to help them deal with the continual stress associated with having a child with a severe disability they were caught in a cycle that perpetuates the incidence of stress and poor psychological well-being.

Analysis of Parental Stress Studies

Five studies from the recent literature describing stress in families of children with disabilities were selected and reviewed. One purpose of the review was to discover if a relationship exists between having a child with a severe cognitive disability and parental stress.

Of the five studies, three (Beckman, 1991; Fisman, Wolf, & Noh, 1989; Floyd & Gallagher, 1997) required the participation of mothers and fathers while the other two (Friedrich & Friedrich, 1981; Hanson & Hanline, 1990) only assessed mothers. Two of the studies (Beckman, 1991; Friedrich & Friedrich, 1981) required that the parents be married as part of their inclusion in the sample. The age range of the children in the five studies reviewed did not exceed 18 years of age. The majority of the studies focused primarily on children younger than age 6 with the rest of the studies looking at older children, each with children having a mean age around 9 years.

One of the articles (Hanson & Hanline, 1990) did not use a control group of parents with children without disabilities. In this study, the researchers reported that the parents of children diagnosed with Down syndrome did not score in the clinically
significant range on the *Parenting Stress Index*. Although no control group was included as a comparison in this study, the results can be compared to the general norm sample in the PSI manual. In comparing the sample from Hanson and Hanline (1990) with the normative sample of mothers from the PSI manual, no significant differences occur with parental stress, income, marital status of mother, education of mother, or mothers’ age.

Three studies (Beckman, 1991; Hanson & Hanline, 1990; Fisman, Wolf, & Noh, 1989) utilized the *Parenting Stress Index* (PSI) to measure stress specifically associated with parenting. Not all studies reported the scores for each section of the index. Hanson and Hanline (1990) used the Child Domain and the Parent Domain but excluded the Total Score and General Life Stress Score. They reported nonclinical levels of stress, although above that of the normative sample in the PSI manual, for parents of children with Down syndrome. Parents of children with disabilities in the other two studies (Beckman, 1991; Fisman et al, 1989) reported clinically significant stress levels, as defined by the PSI manual, although the findings were not consistent across the PSI scores. In Beckman’s study, the mean scores on the Child Domain and the Total Score for both mothers and fathers of children with disabilities were in the clinically significant range. The Parent Domain and General Life Stress Score as well as all the scores for the parents of children without disabilities were not in the clinically significant range. Fisman et al. only administered the Child Domain portion of the PSI. They found that the mothers and fathers of children with autism reported stress in the parent-child relationship in the clinically significant range. The control parents and the parents of children with Down syndrome did not report clinically significant scores although the parents of the later reported more stress than the control parents.
The findings from these studies utilizing the PSI are inconclusive. Significant levels of stress were found in two of the three studies that used the PSI but significant levels of stress were not found on all domains on the PSI. The area that appeared the most effected or elevated was the Child Domain, which looks as the child’s adaptability, acceptability, demandingness, mood, distractibility, and reinforcement of the parent. This is an indication that the child’s temperament might play a significant role in the level of the parents’ stress.

Two studies (Floyd & Gallagher, 1997; Friedrich & Friedrich, 1981) used the Questionnaire on Resources and Stress (QRS); one of the studies (Floyd & Gallagher, 1997) used a shortened five-factor version of the QRS. No criterion was stated in either of these articles to indicate what would be considered a clinically significant score on the QRS. Floyd and Gallagher (1997) added a different perspective by looking at children with mental retardation with behavior problems, children without mental retardation with behavior problems, and children with mental retardation without behavior problems. Using several measures, including the QRS, the researchers found that regardless of the disability status, child behavior problems were associated with higher Parent and Family Problems, Depressive Reaction, and Time Demands scores for mothers, and greater stress associated Dependency and Management for both mothers and fathers. Mental retardation was associated with relatively high levels of certain types of stress and relatively lower levels of other types of stress, in part, depending upon whether the child display significant behavior problems. Specifically, mental retardation was associated with relatively high levels of Pessimism, perceived negative Child Characteristics, and worries about Lifespan Care regardless of child behavior problems. However, when the
child with mental retardation did not have significant behavior problems, the parents reported relatively low levels of Depression, Time Demands, and stress associated with Dependency and Management. The results from the study by Friedrich and Friedrich (1981), using the standard version of the QRS, found that mothers with children with disabilities reported more stress than mothers of children without disabilities. Friedrich and Friedrich did not assess stress levels of fathers.

Friedrich and Friedrich (1981) also used the Psychological Well-Being Index as an indicator of mental health. The results of this measure were consistent with the results of the QRS in this study although not as dramatic. The results still indicated that mothers of children with disabilities experience less psychological well being than mothers of children without disabilities.

In summary, it does appear that parents of children with disabilities experience higher levels of stress than parents of children without disabilities, although the difference is not always significant nor were enough studies reviewed to draw definite conclusions regarding this relationship. The findings in Floyd and Gallagher (1997) add a twist to these findings, suggesting that having a child with behavior problems, in addition to a cognitive disability, might lead to even more parental stress than having a child who has a severe disability but does not exhibit behavior problems. More research in this area would be necessary to determine if higher levels of stress in parents can be attributed to the temperament and behavior problems exhibited by the child with a disability. Other factors often contribute to the amount of stress parents experience. Research has found that the amount of social support and the caregiving needs of the child contribute significantly to the stress levels parents report (Floyd & Gallagher, 1997;
Friedrich & Friedrich, 1981). Hanson and Hanline (1990) found that mothers' stress (both associated with child characteristics and their own experiences) was related to satisfaction with parenting and social support. Mothers who reported higher stress scored lower with respect to satisfaction with parenting and social support. More investigation into these findings would be beneficial in determining what services would are needed for families with children with disabilities.

Taking into account that only five studies were reviewed for this paper, conclusive inferences cannot be drawn. The current review included studies involving a broad range of ages, infancy to age 18 years. This broad range may have interfered with drawing more precise conclusions. One study (Hanson & Hanline, 1990) did not report significant levels of parental stress on any measures given. This study had the youngest population of children with disabilities out of the articles reviewed and did not include a control group to allow for comparison. More research looking at younger children, less than five years of age, which includes a control group would provide more information as to whether these parents experience parental stress at the same rate as parents of older children. One last thing to consider is the marital status of the participants in the studies. Three of the five studies required an intact marriage as an inclusion criterion. Even though two studies allowed for single parents to participate, the majority of the participants were married. If this inclusion criterion was not in place, more difference may have occurred between the study parents and the control parents. Two parents provide support for one another whereas a single parent does not have that added support. Research (Friedrich & Friedrich, 1981; Sabbeth & Leventhal, 1984) has found that having a child with a severe disability may result in negative consequences for the
marriage. The parents in the above studies may have represented a minority of parents of children with disabilities, thus skewing the results of the review. Overall, more research in the area of parental stress would be beneficial in order to draw more definite conclusions.

Review of Parental Depression Studies

Few studies have directly examined parental depression in families with a child with a severe disability. While a parent’s mental health is important and may effect the parent’s ability to effectively care for his/her child with a disability, it is important to keep in mind that there are a variety of factors that may influence the parent-child relationship. The number of children in the home or the amount of stress already present in the parent’s life may have a greater influence on whether the parent reports clinically significant levels of depression than does the severity of a child’s disability. Also, the amount of support a parent receives from his/her family, spouse, and/or local agencies may alleviate a situation that may have resulted in depressive symptoms. It is important to look at the whole family and environment to understand why a parent may or may not be reporting depressive symptoms.

Gath (1972) studied the mental health of siblings of children with congenital abnormalities. In the two years following the child’s birth, two-thirds of the families in the sample had either a parent with a depressive disorder or displayed obvious marital conflict. Frey et al. (1989) conducted research looking a children with disabilities and their parents and found that child characteristics were not related to family adjustment overall, but communication skills of the child were strongly associated with the level of psychological distress reported by fathers (but not mothers). The researchers also
reported that mothers and fathers who rated their own coping efficacy as high, displayed better outcomes in terms of parenting stress, family adjustment, and psychological distress. Three articles will be reviewed and their results will be analyzed to decipher if a relationship exists between having a child with a severe disability and parental depression.

Fisman, Wolf, and Noh (1989)

Fisman and associates (1989) who examined parental stress, as reviewed earlier, also studied parental depression in parents of children with autism and Down syndrome. An outline of this study’s methods can be found in the previous section of this paper.

To measure depression, parents in the study were given the Beck Depression Inventory (BDI). The manual for the BDI presents the following general guidelines for cut-off scores (Beck & Steer, 1987): “Scores from 0 to 9 are considered within the normal range or asymptomatic; scores of 10 to 18 indicate mild-moderate depression; scores of 19 to 29 indicate moderate-severe depression; and scores of 30 to 63 indicate extremely severe depression” (p 7). In this study, mothers of the children with autism and Down syndrome reported higher levels of depression than mothers of the control group children. The average scores of mothers of children with autism were at the lower end of the mild-moderate range of depression. The mothers of the children with Down syndrome and mothers with children without disabilities scored in the normal range on the BDI. There were no significant differences on fathers’ depression scores across the groups with all scores falling in the normal range.

As with the predictors for stress discussed earlier, the patterns of predictors for depression were found to involve reciprocal relationships between parents’ depression,
marital satisfaction, and the parent-child relationship. Depressive tendencies in one spouse were likely to negatively effect the quality of the marital relationship. They found that parents who reported depressive symptoms on the BDI also reported low self-worth, self-esteem, and confidence (as measured by the Identity Subscale of the Waring Intimacy Questionnaire), which negatively effected the parent-child relationship and the parents' perceived success as a parent. More marital problems increased the levels of depression reported by parents. Parent’s depressive tendencies (e.g., self-worth, self-esteem, confidence) also negatively effected the parent-child relationship and the parents’ perceived success as a parent and decreased parent-child relationship quality led to increased depression. The opposite effect was found when parents had a high self-worth, self-esteem, and confidence.

Scott, Atkinson, Minton, and Bowman (1997)

Scott and colleagues (1997) reported on a study they conducted in 1988 with a replication in 1991, which examined psychological distress of parents with an infant diagnosed with Down syndrome. A control group was formed of families who had at least one infant without any obvious medical condition or disability. In both groups, the target infant was less than two years old. The inclusion criteria for parents were that they could read and write English and that they were a two-parent family. Two separate cohorts were used with no overlap of parents for the replication study. The 1988 survey involved 58 control and 88 parents with a child with a disability. The 1991 replication survey involved 70 control and 100 parents with a child with a disability. Subjects were matched case-by-case on socioeconomic status.
Several instruments were used to measure psychological distress. Depression was assessed using the 1979 version of the *Beck Depression Inventory*. Data from this study indicated greater depression for the parents of children disabilities than for parents of children without disabilities although the effect sizes were small. The authors concluded that parenting an infant with Down syndrome might cause less distress than previously thought. The BDI mean scores for all parents in the study fell within the normal range, indicating the parents of children with disabilities did not report clinical levels of depression. The researchers did not look at specific predictors of depression.

**Bristol, Gallagher, and Schopler (1988)**

Bristol, Gallagher, and Schopler (1988) looked at parents of boys with developmental disabilities and parents of boys who were not disabled to see if there was a difference in the adaptation of the family and spousal support. Fifty-six two-parent families participated in this study. Of the 56 families, 31 had a son with a developmental disability and 25 had a son who was not disabled. The children were aged 2 to 6 years of age. Only white, male children under age 6 from intact families in which both mother and father were the biological parents of the child with a disability were included in the study. The mean IQ for the children with disabilities was 55 (SD = 23.63). A group-matched comparison sample of families of boys without disabilities was formed to create the control group. Normal developmental status of these children was confirmed with the results of intelligence tests with a mean IQ of 110 (SD = 13.20). The children in the two groups were matched on child race, gender, and mean child age as well as mean parental age, and socioeconomic status.
The researchers used the Center for Epidemiologic Studies-Depression Scale (CES-D) to measure psychological distress of the parents. Mean depression scores for both mothers and fathers of boys with disabilities were higher than those for their counterparts with children without disabilities, however the differences were not statistically significant. Mothers of the boys with and without disabilities reported higher levels of depression than the fathers in both groups. No norm sample for the CES-D was available for comparisons to be made.

How well mothers of children with disabilities function in terms of depression, marital adjustment, and parenting was found to be related to their perception of their partners’ capacity to be supportive. How well fathers function, particularly as parents, was also related to perceived support received from their wives. Parents who felt supported by their spouses reported lower levels of depression, better marital adjustment, and they functioned better in their role of a parent.

Analysis of Parental Depression Studies

Three studies from the recent literature examining depression in parents of children with severe cognitive disabilities were reviewed. One purpose of the review was to discover if a relationship exists between having a child with a severe disability and the level of parental depression. All three of the studies reviewed reported no clinical differences on measures of depression between the parents of children with severe disabilities and the control parents.

Fisman et al. (1989), using the Beck Depression Inventory, reported higher levels of depression in mothers of children with autism and Down syndrome in comparison to two control groups but only the mothers of children with autism scored in the clinical
range on the BDI with scores in the mild-moderate range. In Scott et al. (1997), parents with children with disabilities report higher levels of depressive symptoms than control parents but the effect sizes were small and neither group reported clinically significant levels of depression. Bristol et al. (1988) examined parental depression in parents of children with cognitive disabilities, using the Center for Epidemiologic Studies-Depression Scale (CES-D). The researchers found the mean depression scores were higher for both mothers and fathers of boys with disabilities than for those parents with sons who were not disabled, however, the differences were not statistically significant.

All three studies looked at both mothers’ and fathers’ reports of depression. A control group was used in each of these studies for the purpose of comparison. Two of the studies (Bristol et al., 1988; Scott et al., 1997) required that the parents in the study be married while the other study (Fisman et al., 1989) allowed for variation in marital status. Bristol et al. (1988) looked only at boys with disabilities and was the only study reviewed that included mean IQ scores of child participants.

Two of the three articles reviewed (Bristol et al., 1988; Fisman et al., 1989) looked at correlates of depression. Bristol et al. (1988) found that with increased spousal support, parents reported lower levels of depression, higher levels of marital satisfaction, and a greater ability to care for the needs of their child with a disability. Fisman et al. (1989) reported similar findings as they found correlations between the depression, the spousal relationship, and the parent-child relationship. Depressive tendencies in one spouse were likely to negatively affect the quality of the marital relationship. Parents who reported depressive symptoms also reported low self-worth, self-esteem, and
confidence (as measured by the Identity Subscale of the WIQ), which negatively effected the parent-child relationship and the parents’ perceived success as a parent.

Considering the limited number of studies reviewed for this section that fit the inclusion criteria, very few conclusions can be drawn from this review. It is obvious that more research is needed in this area in order to better understand the relationship between having a child with a severe cognitive disability and parental depression. None of the studies reviewed reported depression scores in the clinically significant range. No differences appeared to exist between the instruments used to measure depression but this is something that would be important to investigate more thoroughly as well. The Center for Epidemiologic Studies-Depression Scale (CES-D) was only used to look at parents with boys who had a disability. It would be beneficial to know if findings would be similar for parents with girls with disabilities. Another point to consider is the potential influence of social/marital support. Two of the three studies required that the parents of the children be married. A spousal relationship provides some support for the parents and does not leave all the responsibility for caring for the on one person. Studies that allow for more variation in marital status might show a higher prevalence of parental depression.

Review of Marital Relationship Studies

Perhaps one of the more distressing consequences of having a child with a disability is that it might lead to marital difficulties and possibly separation. Researchers have defined and looked at the relationship between having a child with a severe disability and distress in the marital relationship in a variety of different ways. Some research has focused on single parents, looking to see if a higher incidence of divorce
exists in these families (Hirst, 1991). Other studies have looked at marital intimacy and compared parents of children with disabilities to parents of children without disabilities to see if their intimacy level varies in a significant way (Fisman et al, 1989). Still other researchers have looked at “marital adjustment” and the effect a child with a severe disability has on this construct (Frey, Greenberg, & Fewell, 1989; Willoughby & Glidden, 1995).

Much has been written about the impact that a child with a severe disability can have on parents’ marital relationships, but no consistent picture has emerged. Some researchers (Hirst, 1991; Weale & Bradshaw, 1980) have found that having a child with a severe disability results in higher rates of divorce and separation than is found in parents without children with disabilities, while others have found no differences (Cooke, Bradshaw, Lawton, & Brewer, 1986). Three articles will be reviewed and research results will be analyzed to decipher if a relationship exists between having a child with a severe disability and the parents’ marital relationship.

Bristol, Gallagher, and Schopler (1988)

In addition to examining parental depression (reviewed earlier), Bristol, Gallagher, and Schopler (1988) also studied the marital relationship in parents of children with severe disabilities. An outline of this study’s methods can be found in the previous section of this paper.

The 16-item Marital Adjustment Test developed by Locke and Wallace (1959) was used to assess perceived marital adjustment. No effect for gender of parent was found in this study, but parents (both mothers and fathers) of children with disabilities did report more marital adjustment problems than did parents of children without disabilities.
Mothers of boys with developmental disabilities scored below 100, which places them in the clinically significant range or intervention range. Fathers of boys with developmental disabilities scored right at 100 placing them at a borderline range for intervention and clinical significance. The majority of the parents of children both with and without disabilities were not at risk for marital difficulties. Of parents with children with disabilities, 58% of the mothers and 55% of the fathers were not at risk. Of parents with children without disabilities, 76% of the mothers, and 80% of the fathers were not at risk.

Perhaps the most interesting finding of this study is the recognition of the interplay between the spousal support offered and the needs and expectations of the receiving spouse. Regression analyses in the study revealed that, although increased spousal support is clearly related to better personal, marital, and parental adaptation, type of support (e.g., recreational, emotional, intellectual, social, household) as well as “appropriate” support is important. The researchers measured “appropriate” support by looking at the disharmony between current and perceived spousal roles. The results of the analyses indicated that the effectiveness of the type and level of support that was offered depended as much on the recipient as the giver. Parents who felt supported by their spouse (low levels of disharmony between current and perceived spousal support) reported lower levels of depression, better marital adjustment, and they functioned better in their role of a parent.

Friedrich and Friedrich (1981)

Friedrich and Friedrich (1981) who examined parental stress, as reviewed earlier, also studied marital adjustment in parents of children with disabilities. An outline of this study’s methods can be found in the parental stress section of this paper.
The *Locke-Wallace Marital Adjustment Inventory* (1959) was used to measure marital satisfaction. The researchers reported that the mean scores for both the control group and the parents with children with disabilities were in the clinically significant or intervention range (means below 100). The mean for the control group was significantly higher (indicating fewer marital problems) than the mean for the parents with children with disabilities. The difference between the two mean scores was almost 20 points. This significant difference between the groups indicates that the parents of the children with disabilities reported less satisfactory marriages than the parents in the control group. The also researchers found that the parents with children with disabilities indicated higher levels of stress and marital discord as well as less social support and less psychological well being than the parents of children without disabilities which were all found to be a predictors of marital difficulties.

**Fisman, Wolf, and Noh (1989)**

Fisman and associates (1989), who examined parental stress as reviewed earlier in this paper, also studied marital intimacy in parents of children with disabilities. An outline of this study’s methods can be found in the parental stress section of this paper.

The *Waring Intimacy Questionnaire* (WIQ) was used in this study to measure intimacy. The WIQ is a 90 item true-false inventory designed to assess intimacy qualitatively and quantitatively. Both mothers and fathers of children with autism had significantly lower Total Intimacy scores, indicating less intimacy, than the control group parents. The group of parents with children diagnosed with Down syndrome fell between parents of children with autism and the parents of children without disabilities on intimacy scores. No group norms for the WIQ were available for comparison.
Fisman et al. reported that the stress of parenting a child with a severe disability adversely affected marital intimacy, which in turn impacted the parent-child relationship. They also found that depressive tendencies in one spouse were likely to negatively affect the quality of the marital relationship. The researchers in this study hypothesized that parents can alleviate marital problems and improve their marital intimacy by sharing more equally in the care of the child, becoming a cohesive unit, and providing each other with support.

Analysis of Marital Relationship Studies

Based on this review of the literature, it appears that having a child with a severe disability can have negative effects on family relationships, especially the marital relationship. Two of the three articles (Bristol et al., 1988; Friedrich & Friedrich, 1981) reviewed on marital relationships used the Locke-Wallace Marital Adjustment Inventory to measure marital satisfaction. Bristol et al. (1988) found that mothers of children with severe disabilities had a mean below 100 while their husbands scored right at 100 indicating trouble in their marriage. The mean score for both mothers and fathers in the control group was above 100 and thus not clinically significant. Friedrich and Friedrich (1981) reported mean scores for both control parents and parents with children with disabilities in the clinically significant or intervention range (below 100). However, the mean score for the control group was significantly higher than the mean score of parents with children with disabilities indicating that the parents of children with disabilities reported less satisfactory marriages than parents in the control group.

The third article (Fisman et al., 1989) utilized the Waring Intimacy Questionnaire (WIQ) to measure intimacy in parents. Fisman and his colleagues reported significant
differences between the parents of children with autism and parents of control children with the parents of children with autism experiencing a lower amount of marital intimacy. The parents of the children with Down syndrome fell between the two groups and did not significantly differ on total intimacy compared to either group.

All three studies looked at both mothers’ and fathers’ reports of marital satisfaction or intimacy. A control group was used in each of these studies for the purpose of comparison. Bristol et al. (1988) looked only at boys with disabilities and excluded families with girls diagnosed with severe disabilities.

Only a few studies were found to review in this section that met the inclusion criteria. With only three studies reviewed it is difficult to make clear conclusions as to the relationship between having a child with a severe disability and the marital relationship. It is apparent that more research in this area would be of great benefit to better understand the parents’ relationship in conjunction with their child’s disability. Although two of the studies reviewed reported clinically significant findings of lowered marital intimacy with children with disabilities, these two studies used an instrument (Locke-Wallace Marital Adjustment Inventory) developed in 1959, although it is still used quite frequently in research studies. The other instrument, the Waring Intimacy Questionnaire, which when used indicated nonclinical results for parents of children with disabilities, has a more current publication date of 1983. This difference might be because the WIQ is more up-to-date and measuring the quality of the marital relationship more accurately or it might be that the two instruments are really measuring two different variables. Another component to consider is the amount of social support parents are
receiving outside their marital relationship and how much that is making up for difficulties in the marriage.

All of the articles reviewed looked at correlates of marital satisfaction or intimacy. Each of the research findings indicated that parenting a child with a severe disability adversely effects marital intimacy. They found that high levels of stress and/or depression were associated with high levels of marital discord. The researchers also found a strong relationship between the spousal support offered and the needs and expectations of the receiving spouse in regards to marital satisfaction. Bristol et al. (1988) concluded that, although increased spousal support is clearly related to better personal, marital, and parental adaptation, a simple “more support is better” does not adequately describe the relationship between spouses. The effectiveness of support offered was measured by looking at the discrepancy between the spouse’s current (Who is responsible for this task?) and perceived (Who should be responsible?) spousal roles. Lower levels of depression, better marital adjustment, and better functioning in their role of a parent was reported by parents who reported little discrepancy between current and perceived support by their spouse. The results of the analyses indicated that the type and level of support that was offered depended as much on the recipient as the giver. The amount of support given was not as important as whether the receivers of the support felt supported by their spouses. A parent reporting little discrepancy between current and perceived support reported feeling more supported by their spouse and rated their marital relationship and marital satisfaction as higher. The actual amount of support they received did not matter, what mattered was whether they were being supported the way they felt their spouse should support them.
Conclusion

Given the potential for increased demands in caring for a child with a disability, one might expect parents of these children to experience more adverse psychological effects including depression and stress than parents of children without disabilities. However, the results of studies focusing on families with children with disabilities are mixed. Although there is no consensus about whether a child with a disability has an adverse effect on parents, there is no question that the impact of the birth of a child with a disability is considerable. There is a great need for further research in this area to clarify this issue, considering that the parental relationship with the child has such a great influence on child outcomes.

It is also important to investigate the spousal relationship in families of children with disabilities, because the marital relationship is considered to play a major role in the ability of parents to deliver the necessary day to day care associated with children with disabilities. Researchers studying a variety of disabilities have found that a good marital relationship helps parents endure the problems caused by a child’s disability (Belsky, 1984). Friedrich (1979) and Friedrich and Boriskin (1976) found that marital satisfaction was the best overall predictor of successful coping behavior. Blancher, Nihira, and Meyers (1987) reported that mothers of children with severe mental retardation identified their spouse as the greatest source of social support. Similarly, Bradshaw and Lawton (1978) reported that maternal parenting stress was directly related to the mother’s marital satisfaction. The parents’ ability to work together to meet the challenges presented by the child predicts their own well being and the quality of care they provide for the child (Friedrich, Wiltturner, & Cohen, 1985).
One difficulty that arose in this literature review was finding articles that met the inclusion criteria. Many studies included children with severe disabilities but not exclusively. In reporting the findings the children were not always divided by disability or severity of disability which resulted in the study being excluded from the formal review. Considering the limited number of articles that were found that met the inclusion criteria, a section was included in this paper that looked at related articles that did not meet the inclusion criteria but did provide some collaborating for comparison. One of the implications for such an exclusive literature review is that the findings cannot be generalized to the whole population of parents with children with severe cognitive impairments because not enough studies have been conducted. Clearly more research in this area is necessary. It is important to look at parents of children with more severe disabilities and see if their needs are different from parents of children with mild or no disabilities. Although many articles that looked primarily at children with mild disabilities or disabilities were excluded from this review, it was important to keep the criteria because children with severe cognitive impairments are different from those with other disabilities. It is important to find out what difficulties, if any the parents are struggling with and what services and supports are necessary and important to provide for the families.

In looking at the results of this review there are several potential reasons for mixed results regarding levels of stress, depression, and marital problems in parents of children with severe disabilities. One possible reason for low levels of stress and depression reported by parents of children with disabilities is that the social context has gradually improved over the last few decades so that parents of children with mental
retardation receive more social support and are less socially stigmatized. There also have been immense improvements in a variety of services and programs for families with a child who has a disability, such as early intervention and family support systems (Krauss, 1993). These programs may also help to alleviate some marital difficulties. Many of the families recruited for the studies reviewed came from early intervention programs or special education classes. Persons with mental retardation are being integrated slowly but dramatically into the educational system and the work force. The improved family services and increased public acceptance of individuals with disabilities has likely lessened the psychological distress experienced by their parents.

A child with a disability in the family may create stressors not ordinarily found in family life, but research does not indicate total dysfunction within the parents and families of these children. It may be that parents are able to function with the added stressors better than has been suspected. It is also possible that having a child with a cognitive impairment is not as burdensome as once believed and that the parents do not really perceive the added responsibilities as stressors. Another possibility is that the current research is not measuring parental stress, depression, and the marital relationship adequately. The current instruments available to measure these constructs may actually be measuring something different altogether. It is also very possible that parenting a child with a severe disability is not as taxing on the parent or a marriage as one might think. Although research shows that these families tend to report more stress and depression than families of children without disabilities, there is substantial variation in the nature and extent to which individual families report stress. As a result, investigators have become increasingly interested in understanding factors that contribute to variability
in family experiences (i.e., the circumstances under which family stress becomes distress and the conditions that appear to promote successful adaptation). Two variables that clearly emerge as important are the availability of social support and the caregiving needs of the child.

Another reason for nonclinical results may be that the parents included in the studies reviewed may have been receiving some intervention and/or support prior to their participation in the study, which may have decreased their level of stress and depression while supporting their marital relationship. Most studies indicated that the samples of parents with children with disabilities were recruited from developmental and early intervention centers but not all of the studies indicated in what stage of intervention the family was in when recruited. Bristol et al. (1988) recruited new referrals to intervention programs. Fisman et al. (1989) and Beckman (1991) only mentioned that their families with children with disabilities were recruited from early intervention programs but did not state how long they had been engaged in the intervention. Scott et al. (1997) reported that the families they sampled who had a child with a disability were receiving services, which varied but always included an infant stimulation program. The researchers did not have access to the services each family received but they could have included family therapy as it was a service provided at the facility they recruited from. No other possible services were included in the study. The other three studies (Floyd & Gallagher, 1997; Friedrich & Friedrich, 1981; Hanson & Hanline, 1990) did not indicate that their subjects were involved in an early intervention program.

The age of the children sampled in the studies reviewed may also be related to the outcomes. The majority of the children included in the studies reviewed were less than
six years old. Parents of older children with severe disabilities may experience stress and depression at higher levels in addition to reporting more significant marital difficulties as the caregiving needs increase and intensify. For example, as the child gets older he/she will grow in size. If the child still requires dressing, bathing, and toileting assistance the physical demands for the parents increase. The child is also likely to grow stronger and may be more able to physically resist a parent’s attempt to provide caregiving needs. The caregiving requirements are significantly different for an older child when compared with same aged peers. When children are younger they do not vary as much from their peers in their self-help skills. Comparing parents of teenage children, some with children with severe disabilities and others without disabilities, may show a greater variation in stress and depression related to their child considering the greater care demands. This review was not able to examine whether or not age is a factor in parental stress, depression, and marital discord because of the limited number of studies included in the review and the limited number of studies that looked at children above age six.

Although overall, in most studies, the difference in mean scores between the parents of children with disabilities and the parents of children without disabilities were not clinically significant, a mean score does not specifically report the range of scores. Some parents may have still experienced stress and depression or marital dissatisfaction at high rates but they were not with the majority of the parents involved in the study. Looking at individual families and their circumstances is essential to providing sufficient and essential intervention to assist the family in coping. Some studies looked at individual family demographics in order to form comparable control groups and to form general conclusions about particular groups but none of the studies reviewed looked at
each individual family’s results with their individual circumstances to determine appropriate intervention strategies. Although this is not a typical strategy in conducting research it is important when providing for the needs of individual families. Although the majority of parents may not experience stress and/or depression at a clinically significant level it does not mean that an individual parent could not experience significant levels of depression and/or stress with the birth and care of a child with a severe disability.

Some specific and direct interventions for children with various disabilities have been found to reduce the amount of stress, depression, and marital dissatisfaction experienced by parents. Singer, Irvin, and Hawkins (1988) found stress management training helpful to parents of children with severe disabilities. Rimmerman (1989) found that providing home-based respite services for children with disabilities was associated with a reduction in maternal stress as well as enhancement of mothers’ coping resources. Baker, Landen, and Kashima (1991) researched the effects of parent training on families of children with mental retardation and they reported small but statistically significant decreases in reports of symptoms of depression, parent and family problems, overall family stress, and dissatisfaction with the family’s adaptability following intervention.

Investigators have consistently reported that the amount of stress families report is related to the social support they receive, particularly informal social support which includes spouses (Beckman & Pokorni, 1988; Crnic, Friedrich, & Greenberg, 1983; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Dunst, Leet, & Trivette, 1988). In general, the formal review and the related research review in this paper found that families who report higher levels of social support also tend to report lower levels of
stress. As a result, social support has increasingly been identified as a mediator of stress which was supported in the formal review of this paper. Beckman (1991) found that unlike informal support (e.g., from neighbors, friends, spouse), formal support (e.g., from professionals, agencies) was not significantly associated with lower levels of stress on the Parent or Child domains of the PSI. This finding is disturbing because it leads to questions concerning the extent to which service providers are meeting the needs of families. In Beckman’s study, he found that for fathers, but not mothers, formal support was associated with a decrease in General Life stress. This suggests that different or additional sources of support may facilitate coping for fathers. Beckman theorized that informal support may mediate stress by providing relief from the child’s caregiving requirements. Friedrich and Friedrich (1981) reported that the groups of parents who had children with disabilities reported a less satisfactory marriage, had less social support, and were less psychologically healthy than the group of parents with children without disabilities. Hanson and Hanline (1990) found that mothers who indicated that they did not have a partner in parenting reported less social support, than those with a partner.

Having a child with a disability may not be the only factor or the most significant factor in predicting parenting experiences. Other factors, like the lack of support, may present a stressful situation.

Caregiving needs have also been consistently associated with increased stress in families of children with disabilities (Beckman, 1983; Beckman & Pokorni, 1988) although children with severe disabilities have not been exclusively studied in this area. For example, Beckman (1983) found that the number of additional or unusual caregiving demands was highly correlated with the amount of stress reported by mothers of infants
with disabilities. Beckman (1991) found that mothers of children with disabilities reported higher levels of stress with increased caregiving requirements (e.g., feeding, medical care). Willoughby and Glidden (1995) reported greater father participation in childcare was associated with greater marital satisfaction for both mothers and fathers in their study.

Implications for School Psychologists and Other School Practitioners

Parents with a child with a disability confer with their child’s teacher to learn how their student is managing at school; teachers also serve as resources for parents who wish to know how they can best educate their children at home. But many parents need more than just help with their child’s academics. They sometimes need a mental health professional to assist them with some of the dilemmas they often confront. Such dilemmas can include (a) the stress of having a child with a disability in a family, which may be more than the family can bear physically, financially, and psychologically; (b) feelings of guilt on the part of parents thinking they caused their child to be disabled; (c) siblings who may be at risk for psychological problems when there is a brother or sister with a disability in the family; (d) the differentiated roles and reactions of mothers and fathers to a child with a disability; (e) insensitive parent-professional encounters that leave long-term scares on the family; and (f) the reactions of extended family members, friends, and those in the immediate community, which affect family adaptation.

Harris (1984) warned service providers about a narrow, behaviorally oriented child management focus for parents of children with disabilities. Harris argued that practitioners who ignore broad family issues are likely to encounter frustration and failure
in working with children with disabilities and their families. If a therapist attempts to teach a mother how to help her child with a disability learn to feed and dress herself but ignores the mother’s depression about the child’s diagnosis and the father’s lack of involvement in the family as his response to stress, a situation is created which is likely to generate failure. Clinicians who work with parents do need to help them manage their children successfully, but they should not lose sight of the family’s response to its special circumstances.

Many of the conclusions derived from this review of the literature are relevant for professionals who are involved in the field of disabilities, especially those at schools who interact frequently with families, such as school psychologists. First, professionals must begin to differentiate between those variables which are relatively fixed (such as family SES or child gender) and, therefore, offer limited opportunities for intervention, and those variables which can be changed to enhance family adaptation and coping. For example, while professionals cannot change the composition of a family unit, they can assist its members to develop healthy communication skills and to acquire competence in problem solving and advocacy. As well, professionals can help parents to discover their own strengths and existing resources to meet family needs; that is, professionals can help parents discover what “works” for them.

Practitioners can also help educate parents about stress and depression. They can coach them on ways to handle the added pressures in their life and recognize when they may need professional help. Practitioners can also provide resources for a variety of support services. It is clear that interventions must go beyond isolating specific variables
additional support from outside resources as well as provide parent training and support to the parents.

Often it is a school psychologist who diagnoses children with cognitive impairments and other severe disabilities. This unique position gives the psychologist a great opportunity to provide support and recommendations to help the parents to work together to remain healthy and intact as a family. Research clearly favors the assumption that social support is constructive in moderating the effects of personal and family stress (Barakat & Linney, 1992; Trivette & Dunst, 1992). In families of children with disabilities, social support has been found to have positive effects on maternal and family adjustment, as well as on parenting styles, parental attitudes and expectations, and child behavior and development (Barakat & Linney, 1992; Trivette & Durst, 1992). In addition, communication with other parents of children with disabilities enables many parents to embrace their feelings and concerns as normal, and obtain non-judgmental acceptance and nurturance (Barakat & Linney, 1992; Todis & Singer, 1991). However, support may be difficult to find (Donovan, 1988). The school psychologist working with these families can question parents on the current level of support the family is receiving and identify areas where parents would like more support, if support is needed. Psychologists can encourage parents to join support groups, talk to other parents with children with disabilities, and find support in their extended family and the community. Also, the psychologist or other professional working with these families can help them find more formal types of support, such as respite care, parent training, and counseling.

In light of the findings in this review, parents may not experience as high of levels of stress and depression as previously thought but they will still benefit from the
additional support that mental health professionals and school personnel can provide. The services parents may need are not the intensive interventions, such as psychotherapy and medication, which may have been assumed to be needed. More support is needed in the families than psychological intervention. Mothers and fathers need the support of their spouse in child care responsibilities and in sustaining their marriage as well as respite services, educational training on their child’s disability and how to best teach and work with their child. School psychologists can assist families in this area by providing parent training, education, and resources as to where to find respite services for their child. Informal support from others besides professional agencies and schools such as parent support groups, support from extended family, and support from friends and the community are important. Mental health, early intervention, and school specialists can encourage families to develop and utilize their current support systems as well as aide in developing a greater support network. This can be done by educating the parents about informal support and how it has been found to be essential in families with children with disabilities. Also, encouraging and educating parents about their essential role in supporting one another and the benefits their spousal support will have on their entire family. Assisting families in gaining informal support may be a more difficult intervention to provide for families as it is a burden the parent is more responsible for taking care of by finding and maintaining their informal support system.

Many parents of children newly diagnosed with disabilities have expressed bewilderment over the process of adapting to and coping with their new parenting roles, as well as managing their own personal lives, their marriages, their work, and their immediate and extended families. This review was designed to provide parents of
children with disabilities and the professionals who work with them, a more comprehensive portrayal of the relationship between having a child with a severe cognitive disability and parental stress and depression. Although few conclusions that can be generalized were made because of the lack of extensive research in this area, a better picture as to what parents of children with disabilities may be experiencing has been painted. The results of the review indicate that informal social support, which includes support of a spouse, family, friends, and neighbors, may create a buffer against parental stress and depression. More research is needed to determine what amount and level of support is necessary to alleviate families with the additional burden a child with a severe disability may place on a family. The research reviewed showed that some families do experience stress and depression at clinically significant ranges as well as difficulty in the marital relationship while other studies did not. Future research looking at whether this difference really exists and for whom (e.g., which parents are most at-risk) will be essential for providing effective and efficient services and support to families.
References


