Caretaking Burden and Social Support: Comparison of Mothers of Infants With and Without Disabilities

Data concerning mothers' perceptions of child caretaking burden, fathers' participation in child caretaking, and satisfaction with social support were analyzed for a 202 member sample consisting of mothers of infants with Down syndrome, motor impairment, developmental delay, and no known disabilities. The results were contrary to some common findings from the literature. Significant differences among the four groups were found on difficulty of and time devoted to caretaking, number of tasks with which fathers helped, and satisfaction with support from family, friends, and community groups. The programmatic and policy implications of these findings were discussed.

Professionals and social science researchers are becoming increasingly interested in understanding how families cope with or adapt to the birth of a child with a disability. Although the family home has always been the primary location in which children with disabilities have been raised, programs and policies to support the efforts of families have been developed only over the last decade (Krauss, 1986; Upshur, in press). Although there are studies describing the positive aspects of parenting a child with disabilities (Kazak & Marvin, 1984; McHale, Sloan, & Simeonson, 1986), most of the literature has focused on the negative outcomes for families because of the more difficult and atypical caretaking responsibilities. A review of the literature reveals three characteristics that are often ascribed to families of children with disabilities that distinguish them from families with children who do not have disabilities: (a) more difficult caretaking burdens (Cron, Friedrich, & Greenberg, 1983; Farber, 1970; Gallagher, Beckman, & Cross, 1983; Kazak & Marvin, 1984); (b) different caretaking roles performed by the father (Gallagher, Cross, & Scharfman, 1981; Tallman, 1965; Yoyogin, 1982); and (c) more social isolation (Birnbaum, 1970;}

Marji Erickson
Brandeis University
Carole C. Upshur
University of Massachusetts at Boston
Featherstone, 1980; Gallagher, Beckman, & Cross, 1983; Gayton, 1975; McAndrew, 1976).

**More Difficult Caretaking.** The rearing of a child with a disability has been associated with physical and emotional strain as well as financial burden (Crnic, Friedrich, & Greenberg, 1983; Farber, 1970; Goldberg, Marcovitch, MacGregor, & Lojowske, 1986; McCubbin et al., 1983). Gallagher, Beckman, and Cross (1983) found a significant association between the presence of additional or unusual caretaking demands for infants with disabilities and high levels of parental stress. Kazak and Marvin (1984) found that mothers of 7- and 8-year-old children with spina bifida perceived their children as being more demanding than did a comparison group of mothers of children without disabilities. In addition, Breslau (1983) reported that married mothers of children, ages 3 to 8 years, with cystic fibrosis, cerebral palsy, myelodysplasia, and multiple physical handicaps spent more time on household tasks (e.g., cooking, feeding, cleaning) than did mothers of children without disabilities and that they spent an additional 4 hours per week, on average, administering home therapy.

**Different Caretakers Roles for Fathers.** For most families, fathers are less involved in caretaking tasks than are mothers (Bristol & Gallagher, 1986; Ninio & Rinott, 1988; Parke & Tinsley, 1981; Pleck, 1983). Greater than average involvement in household tasks and child care has been noted, however, on the part of fathers of four or more children (Campbell, 1970) and fathers of preterm infants (Yogman, 1982). In addition, Tallman (1965) found that fathers of children with disabilities became highly involved in child care but only with boys. Conversely, Gallagher, Scharfman, and Bristol (1984) and Kazak and Marvin (1984) found no difference in the level of father involvement in child care tasks with children with and without disabilities.

**Social Isolation.** McAndrew (1976) described parents' accounts of their deteriorating relationships with family and friends after the birth of a child with a disability. Other investigators have focused on family members' smaller friendship networks and increased reliance on extended family (Hewett, Hewett, & Newson, 1970; Kazak & Marvin, 1984), as well as their feelings of alienation from formal support services (Darling, 1979; Featherstone, 1980; Turnbull & Turnbull, 1985; Waisbren, 1980). In addition, Kazak and Wilcox (1984) found that in comparison to families with children without disabilities, the social networks of families with children with disabilities were smaller. Other researchers, however, have suggested that an individual's satisfaction with each source of support, as opposed to the number of sources, is a better predictor of a network's quality (Barrera, 1981; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Dunst, Trivette, & Cross, 1986).

Despite the prevalence with which these characteristics have been discussed in the literature, researchers have increasingly acknowledged that families of children with disabilities should not be considered a homogeneous group in terms of perceived stress and articulated needs (Turnbull, Summers, & Brotherson, 1986; Upshur, in press). Further, three methodological issues make generalizations based on previous research somewhat unreliable. First, many of the studies cited lack a comparison sample of families without children with disabilities. Second, each study was focused on a particular age range of children, making generalizations to other age groups difficult. Finally, the samples utilized consisted of children with widely varying disabilities rather than children with similar kinds of disabilities.

The present study was designed to explore systematically and empirically the three aforementioned characteristics by making comparisons between a group of mothers of infants without disabilities and three groups of mothers of infants with different kinds of diagnosed disabilities. Specifically, we addressed the following questions: (a) Do any of the mothers in the three groups with infants who have disabilities perceive child caretaking tasks as more difficult or as more time-consuming than do mothers of infants without disabilities? (b) Do fathers in any of these three groups perform more child caretaking tasks than do fathers of infants without disabilities? (c) Do any of the mothers in the three groups display different patterns of satisfaction with their social support networks than do mothers of infants without disabilities?

**Method**

**Sample**

Our families of infants with disabilities were part of the Early Intervention Collaborative Study (EICS), which is currently being conducted at the Department of Pediatrics at the University of Massachusetts Medical School with the assistance of 29 publicly supported early intervention programs in Massachusetts and New Hampshire.
The purpose of this multi-year project is to investigate the impact of early intervention services on a variety of child and family outcomes. Families of infants without disabilities were recruited through four pediatric practices in Massachusetts.

The total sample consisted of 202 families with children who were 2 years of age or younger. Analyses were conducted for four groups of mothers of children with (a) Down syndrome \( (n = 33) \), (b) motor impairment \( (n = 43) \), (c) developmental delay \( (n = 41) \); and (d) no known disabilities \( (n = 85) \). Complete data were available for 175 cases; the remaining 29 cases had data missing on only one variable. Mean substitution for the value of the missing variable based on the child's group membership was employed with these 29 cases to maintain a constant sample size for the analyses.

In general, these families were predominantly white (93.1% of mothers, 92.1% of fathers, 92.5% of infants), two-parent families (92.6%) with fathers who were employed full-time (89.6%). The mean family income was $25,280. Slightly more than one half of the mothers (57.4%) and fathers (58.5%) were Catholic, and one half (48.8%) of the mothers listed their primary occupation as homemaker. Slightly more than one half (53.5%) of the children were male, and more than one third (30.1%) were only children.

Table 1 presents selected characteristics of the families by group. One-way analyses of variance post hoc Scheffé tests for pairwise comparison of means were conducted to examine these characteristics. There were statistically significant differences across the study groups for four variables. First, although no differences were found in terms of the number of children in each family who were older than the sample child, the average age of the sample child differed significantly. For the three groups of infants with disabilities, the differences correspond to the ages at which children with these disabilities are typically referred to early intervention programs.

The children with Down syndrome were significantly younger than the comparison sample children as they are typically diagnosed at birth and referred very early. The children with developmental delay, on the other hand, were significantly older than the comparison sample. For these reasons, another set of analyses were conducted utilizing two subsamples of the comparison group. The first subsample was age-matched to the group of children with Down syndrome; the second subsample was age-matched to the group of children with developmental delays.

Significant differences were also found in terms of mothers' age and average yearly income across the four groups. Mothers of infants with Down syndrome and infants with developmental delays were older than the mothers of infants in the other two groups. Families in the comparison sample had the highest average yearly income. However, none of these pairwise relations were statistically significant using post hoc Scheffé tests.

Finally, for children with disabilities, the severity of disability across the groups differed significantly. (Severity of disability was not measured for the infants in the comparison group.) Severity was calculated as a composite of the

### Table 1

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Down Syndrome ( (n = 33) )</th>
<th>Motor Impaired ( (n = 43) )</th>
<th>Developmental Delay ( (n = 41) )</th>
<th>Comparison ( (n = 85) )</th>
<th>F²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average age (months)</td>
<td>3.53*</td>
<td>2.25</td>
<td>11.49</td>
<td>4.70</td>
<td>15.33*</td>
</tr>
<tr>
<td>No. of older children</td>
<td>1.15</td>
<td>1.09</td>
<td>0.84</td>
<td>1.04</td>
<td>1.00</td>
</tr>
<tr>
<td>Severity of disability</td>
<td>1.58</td>
<td>0.61</td>
<td>2.05</td>
<td>0.75</td>
<td>2.24</td>
</tr>
<tr>
<td>Mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average age (years)</td>
<td>30.55</td>
<td>4.44</td>
<td>27.67</td>
<td>5.34</td>
<td>30.26</td>
</tr>
<tr>
<td>Years of education</td>
<td>14.09</td>
<td>2.71</td>
<td>13.35</td>
<td>2.42</td>
<td>14.22</td>
</tr>
<tr>
<td>Father</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average age (years)</td>
<td>31.88</td>
<td>6.22</td>
<td>30.86</td>
<td>6.33</td>
<td>31.99</td>
</tr>
<tr>
<td>Years of education</td>
<td>14.39</td>
<td>3.25</td>
<td>13.48</td>
<td>2.76</td>
<td>14.20</td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average yearly income (dollars)</td>
<td>24490</td>
<td>11447</td>
<td>23376</td>
<td>12027</td>
<td>24604</td>
</tr>
</tbody>
</table>

*All dfS = 3,196. **1 = low severity, 2 = moderate severity, 3 = high severity. ³ Severity of disability is significantly greater at the .05 level between the indicated diagnostic group and the Down syndrome group. ¹ p < .05. ² p < .001.
child's score on the Bayley Scales of Infant Development (Bayley, 1969) and the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984). The children in the Down syndrome group were significantly less severely disabled than either the motor impaired or the developmentally delayed group.

Measures

All measures were self-reports based on others' perceptions. The child caretaking and demographic information on the three groups of children with disabilities was collected by interview during home visits conducted by the EICS research staff within the 2-week period following each child's referral to an early intervention program. The Social Support Scale (adapted from Dunst, Jenkins, & Trivette, 1984) was self-administered and returned by mail to the EICS project office. For the comparison sample, mothers completed three questionnaires at their pediatrician's office while they waited for their child's appointment.

The questionnaire regarding caretaking tasks was derived from the Family-Focused Intervention Rating Scales (Dunst, 1985). The tasks covered included feeding, bathing, dressing, sleeping, napping, and special activities (e.g., home activities recommended by physicians, nurses, early childhood educators, or physical or occupational therapists). Perceived difficulty of performing each type of task, excluding the special activities, was measured on a 4-point scale (1, no difficulty; 2, some difficulty; 3, moderate difficulty; and 4, extreme difficulty). Mothers were also asked to estimate how much time it took to feed, bathe, and dress their child; how much time it took to perform the recommended special activities; and how much time they had to themselves during a typical day. Finally, the frequency with which the father performed each task (excluding special activities) was measured on a 3-point scale (1, never; 2, sometimes; and 3, most of the time).

A separate scale, adapted from the Family Support Scale (Dunst et al., 1984), was used to measure satisfaction with various sources of support. Mothers were asked to rate each of 14 sources listed on a 0- to 4-point scale (0, not at all helpful; 1, somewhat helpful; 2, moderately helpful; 3, quite helpful; and 4, extremely helpful). Mothers could also indicate that the source of support was "not available" or "available but no contact." The third questionnaire covered basic demographic information.

Methods of Analysis

Several methods were used to analyze the data. Data-reduction techniques were employed to create the dependent measures used to address each research question. For the first question, principal component analyses were conducted on the five variables measuring perceived difficulty of care. The results indicated that these variables could be grouped into two factors: Sleeping and Napping and Feeding, Bathing, and Dressing. Based on these factors, two dependent measures were created by averaging the difficulty ratings assigned to the tasks associated with each factor.

In order to further examine this question, we calculated two additional dependent measures using the estimates regarding the amount of time a mother needed to perform the various caretaking tasks each day. First, the total amount of child caretaking time per day was obtained by summing the minutes estimated to perform the tasks of feeding, bathing, dressing, and special activities. The second measure added together only the minutes estimated to perform the first three tasks. A final dependent measure was the estimated amount of time, in minutes, that mothers felt they had to themselves each day.

For the second question the overall frequency with which fathers were reported to perform any one task most of the time ranged from 3.0 to 15.8%. Thus, the 3-point scale used to measure the frequency with which a father performs the tasks was converted to a 2-point scale (0, never performs the task and 1, sometimes or most of the time performs the task). The dependent measure was created by summing the values reported on the converted scales across all the tasks.

For the third question principal component analyses were conducted on the variables measuring satisfaction with social support sources. This factor analytic technique indicated that these variables could be grouped into three factors that roughly correspond to Bronfenbrenner's (1986) model of a social support network: (a) family (including spouses, maternal and paternal relatives, other children, and babysitters); (b) friends (including neighbors and other parents); and (c) community groups (including, for example, community services, doctors, social groups, parent groups, churches). Based on these factors, three dependent measures were created by averaging the satisfaction ratings assigned to each of the three sources of support.

One-way analyses of variance with post hoc
Schiffé tests for pairwise comparisons of means were used to explore the three research questions. The nine dependent measures previously described were examined. Additional one-way analyses of variance and t tests were also conducted to determine the extent to which the age of the infant and the severity and type of disability had an impact on child rearing, father’s child care activities, and social support.

**Results**

With regard to the first question (perceived difficulty of care), it is important to note that the vast majority of mothers perceived little child caretaking difficulty. In fact, no more than 5.1% of the mothers of children with disabilities said that any one task was either extremely or moderately difficult.

As indicated in Table 2, however, there were statistically significant differences across the four groups with respect to perceived child caretaking difficulty of feeding, bathing, and dressing, and caretaking time. In relation to the comparison sample, different patterns emerged for each of the disability groups.

In the overall analysis presented in Table 2, although the mothers of infants with Down syndrome did not report more caretaking difficulty than did comparison mothers, they did report significantly greater caretaking time on both time variables. Given the fact that children in these two groups were significantly different in age, t tests comparing the Down syndrome group to infants of similar age in the comparison group (n=25) were performed. Only the measure of total caretaking time, which includes the time it takes to perform special activities, was significantly greater for the Down syndrome group, $t = 2.34, p = .023$. In addition, mothers of infants with Down syndrome reported more difficulty in feeding, bathing, and dressing their child than did comparison mothers, $t = 2.12, p = .038$. Finally, the variable measuring total time to self was significant; mothers of infants with Down syndrome reported less time for themselves than did comparison mothers, $t = 2.46, p = .018$.

Mothers of infants with motor impairments did not differ significantly from mothers of comparison sample infants in terms of perceived child caretaking difficulty in the overall analysis. Reported total caretaking time, however, was significantly greater for the motor impaired group than for the comparison sample. The ages of infants in these two groups were not significantly different.

Mothers of infants with developmental delays comprised the only group to report significantly greater child caretaking difficulty with feeding, bathing, and dressing than did the comparison sample in the overall analysis. This difference remained significant when a $t$ test was performed to compare the developmentally delayed group to an age-matched subset of the comparison sample ($n=57$); $t = 3.20, p = .002$. No significant differences in caretaking time were found between these two groups in either the overall analysis or in the subsample analysis controlling for the child’s age.

Analyses were also conducted within each of the three groups of children with disabilities to test for differences in caretaking time and difficulty of care by severity of disability. No statistically significant differences were found.

For the second question (caretaking by fathers), a statistically significant difference was found across the four study groups, $F = 5.36, p = .001$. Post hoc Schiffé tests indicated that fathers of infants with motor impairments performed signific-

<table>
<thead>
<tr>
<th>Table 2: One-Way Analysis of Variance of Perceived Difficulty and Time Required for Child Caretaking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristic</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>Perceptions of caretaking difficulty</td>
</tr>
<tr>
<td>Sleeping and napping</td>
</tr>
<tr>
<td>Feeding, bathing and dressing</td>
</tr>
<tr>
<td>Total caretaking time (minutes)</td>
</tr>
<tr>
<td>Caretaking time without special activities (minutes)</td>
</tr>
<tr>
<td>Total time to self (minutes)</td>
</tr>
</tbody>
</table>

*All dfs = 3,196.  **p < .01.  *p < .05.  Includes time for feeding, bathing, dressing, and special activities.  "p < .001.
icantly fewer tasks than did fathers of infants in the comparison sample. Fathers of infants with Down syndrome and of those with developmental delays performed, on average, the same number of tasks as the comparison sample fathers in both the overall analysis and in the subsample analyses controlling for age. In addition, none of the differences in the number of tasks performed by the father was related to severity of disability within any of the three disability groups.

On the third question (satisfaction with social support), mothers of infants with Down syndrome reported significantly greater satisfaction with support from friends and community groups than did comparison group mothers (see Table 3). These differences remained significant even after age was controlled. Mothers of infants with motor impairments and developmental delays were more satisfied with support from groups than were mothers of infants without disabilities. In the subsample analysis mothers of infants with developmental delays were also more satisfied with the support they received from their friends than were comparison mothers of age-matched infants. Finally, no differences with respect to satisfaction with social support were associated with the child's severity of disability.

Discussion

The purpose of this study was to explore three characteristics commonly attributed to families with children with disabilities. In contrast to previous research on family needs, our findings indicate that mothers' perceptions of child caretaking burden; father's participation in child care activities; and support received from family, friends, and community groups varied in relation to the type of the child's disability and the age of the child. Although our sample consisted of a relatively homogeneous group of intact families with moderate incomes, our results have important implications for understanding individual differences in families and for planning services that recognize such differences.

Although child caretaking was not rated as being very difficult by mothers overall, there were modest but statistically significant differences in caretaking burden among the groups. Mothers of children with Down syndrome and with developmental delays reported more caretaking difficulty than did mothers of non-disabled infants of similar age. Although mothers of infants with motor impairments did not report more difficulty in caretaking tasks, they did report more time required for caretaking compared to mothers of infants without disabilities when time for special activities was included. Mothers of children with Down syndrome also reported more total caretaking time and less time to themselves than did mothers of non-disabled age-matched infants.

Thus, for each group of mothers of infants with disabilities, there appeared to be a somewhat different pattern of caretaking burden compared to mothers of infants without disabilities. This finding illustrates two points. First, although caretaking burden was originally conceptualized as having elements of both difficulty and extra time expenditure, mothers' reported perceptions of time and difficulty were inconsistent. Second, the different patterns of caretaking burden not only reflect the unique impact of infants with different disabilities on their caregivers. For example, children with Down syndrome have been found to have damped affect and to provide fewer cues to caregivers (Bridges & Cicchetti, 1982; Gunn & Berry, 1985). The reported differences in caretaking difficulty and time spent may be explained as a result of the extra effort required to engage the infant with Down syndrome. On the other hand, the incidence of behavior problems among children with disabilities is high (Rutter, Tizard, & Whitmore,

Table 3
One-Way Analysis of Variance of Satisfaction With Social Support

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Down syndrome (n=35)</th>
<th>Motor impaired (n=43)</th>
<th>Developmental delay (n=41)</th>
<th>Comparison (n=85)</th>
<th>F*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Average satisfaction with support from</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>3.04</td>
<td>0.77</td>
<td>2.38</td>
<td>0.76</td>
<td>2.60</td>
</tr>
<tr>
<td>Friends</td>
<td>2.56*</td>
<td>1.10</td>
<td>1.96</td>
<td>0.91</td>
<td>2.05</td>
</tr>
<tr>
<td>Community groups</td>
<td>3.08*</td>
<td>0.87</td>
<td>2.73*</td>
<td>0.91</td>
<td>2.67*</td>
</tr>
</tbody>
</table>

*All dfs = 3,88. ** p<.01. *** p<.001.
The infants with developmental delay in our sample were, on average, about 15 months old and, thus, were at an age when behavior problems begin to become more marked. The reported differences in terms of difficulty of caretaking burden, but not time expenditure, between infants with and without disabilities in this age range may thus be due to behavioral characteristics rather than specific caretaking needs. These hypotheses merit further empirical research utilizing longitudinal data.

In terms of the second research question, we found that, in general, fathers of infants with disabilities did not perform more caretaking tasks than did fathers of infants without disabilities. The only significant finding was that fathers of children with motor impairment were reported to perform significantly fewer tasks than did fathers of infants without disabilities. This result is somewhat puzzling and does not seem to be related to gender or severity of disability. One possible explanation has to do with the fact that these families had the lowest average yearly income and the fewest years of paternal education (see Table 1). Although these findings were not statistically significant, they indicate that there may be economic factors that impinge on a father's ability to participate in child care activities. Other investigators have, in fact, found a positive relation between father's education, socioeconomic status, and involvement in caretaking tasks (Riley, 1985; Russell, 1981).

Finally, we did find some surprising differences in satisfaction with social support. Mothers of infants without disabilities were significantly less satisfied than mothers of infants in the three disability groups with support from the community. One explanation for this result may be that at the time of data collection, the families with children with disabilities had recently been enrolled in early intervention programs which offer a number of support services to families. Mothers of infants with Down syndrome and with developmental delay also reported more satisfaction with the support of friends. These findings may explain, in part, the lack of dramatic differences reported concerning caretaking burden. We note, however, that these children were very young. Future researchers should investigate the long-term stability of social support.

In conclusion, we have shown that the impact of a child with a disability is a complex one that cannot be easily described or predicted. These findings have implications for service delivery in that they support the necessity for individualized service plans tailored to varying family strengths and needs. Just such a service philosophy has been codified in the mandates of P.L. 99-457 that encourage states to develop comprehensive systems of early intervention services. One of the provisions of this law is the requirement of an Individual Family Service Plan (IFSP) as the mechanism for determining services, rather than focusing solely on the child's characteristics, and to involve the family in the plan's development. Our findings confirm the appropriateness of acknowledging individual family differences and challenges. The findings of previous research regarding the extent to which very young children with disabilities engender family isolation or pose substantial caretaking burdens beyond those of all infants and toddlers.

References


Research, programs, and policy issues (pp. 45–65). Baltimore: Brookes.


