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## Financial and Time Costs to Parents of Severely Disabled Children

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This project was supported by BRSR 0696522559 awarded by the Biomedical Research Support Grant Program, Division of Research Resources, National Center for Research Resources, National Institutes of Health and by Sigma Theta Tau, Zeta Chapter.

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## Synopsis.....

*This paper considers the financial burden of parents caring for severely disabled children. A model to predict parents' out-of-pocket expenses and caregiving time demands is described.*

*Discriminant analysis correctly classified high and low group membership for out-of-pocket expenses and caregiving time at 72 percent and 77 percent, respectively. Expected rates were 50 percent. Time spent caregiving was the best predictor for out-of-pocket expenses, and out-of-pocket expenses was the best predictor of caregiving time.*

*A need-based approach for the distribution of resources that recognizes and adjusts for caregiving time and out-of-pocket costs is recommended.*

**I**N THE UNITED STATES, an estimated 10-15 percent of all children have a chronic illness, and 1-2 percent have a severe chronic illness (1). Because the care of these children is often demanding and expensive, many families face financial difficulties. For example, Newacheck and McManus (2) re-

ported that children limited in their activities use more medical services than other children, especially hospital-based services and nonphysician health services, and that out-of-pocket expenses were two to three times higher. They also report that there is an uneven distribution of financial

burden among families with disabled children, especially for those families without insurance.

Although most families rely on third-party payers to cover medical expenses, the extent to which these expenses are covered varies, with families often needing to cover some medical expenses. In addition, disease-related nonmedical expenses such as transportation to medical facilities, special diets, and hotel and restaurant expenses when the child is hospitalized can be costly and yet are frequently not covered by third-party payers. Thus, most families finance some portion of their child's total medical care.

In addition to the financial burden, families with severely disabled children usually have excessive caregiving time demands placed on them because of the child's medical vulnerability. These demands often mean parents forfeit time spent in other ways such as employment and recreation and time for other children, spouse, and friends in order to provide the child's care (3).

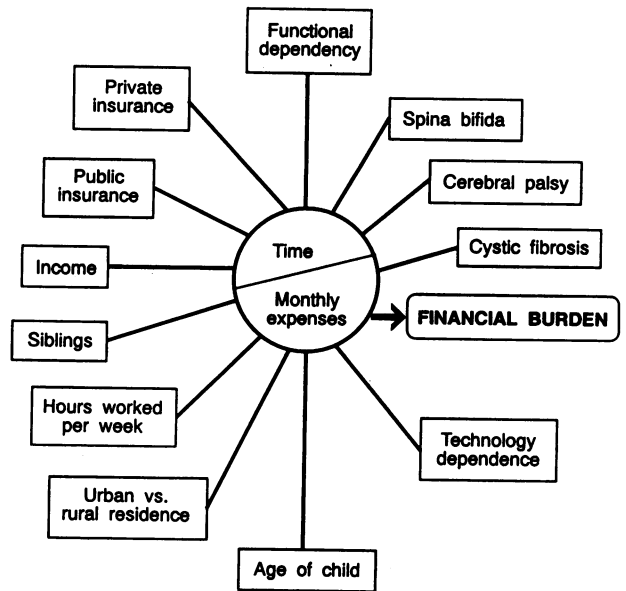
The burden that families with disabled children have in terms of additional out-of-pocket expenses and caregiving time has been difficult to quantify because collecting that data is time consuming, costly, and of necessity invades the family's privacy. Further difficulties arise when studying caregiving time costs because information is lacking on parental time costs for nonhandicapped children, which would then present "benchmarks" for comparison (3). For these reasons, studies of financial burden have seldom included estimates of families' out-of-pocket expenses and caregiving time (4). However, if there is an uneven distribution of financial burden among families as suggested by Newacheck and McManus (2), identification of factors that contribute to families' burden should help guide policy for community or State programs.

The purpose of our report is to describe a model designed to predict the average out-of-pocket expenses and caregiving time costs incurred by those who provide care for a severely disabled child. The model depicts the independent variables that would influence the overall financial burden of parents, such as family income, hours employed, and type of third-party reimbursers. The dependent variables are (a) the parents' average monthly out-of-pocket expenses and (b) the caregiving time costs incurred by a parent in the provision of care (fig. 1).

### Sampling

Caregivers of severely disabled children in the State of Minnesota who had submitted applications

Figure 1. Variables Initially Included in the financial burden model of out-of-pocket expenses and time demands



to Minnesota's Services for Children with Handicaps (SCH) Program were sampled. SCH provides specialized medical care throughout the State and acts as a reimbursers for medically and financially needy children who require medical care, equipment, or supplies not covered by their families' third-party reimbursers.

All Minnesota families are eligible to apply for SCH services. However, eligibility, which is granted on a sliding fee scale, is based on a formula which assesses after tax income, number of family members, medical expenses, and other third-party reimbursement opportunities. Thus, this population is typically lower middle class, although higher and lower income families can obtain assistance.

From July through October 1988, SCH received 964 applications. Of these applications, the first 221 families who met study criteria were selected to participate in this study. A master's prepared nurse consultant employed by SCH, using study criteria, selected severely disabled children from the list of applicants. The cover letter to parents requested that they review the study criteria and complete the survey if they met all criteria. Study criteria were as follows:

1. The child must be 18 years or younger.
2. The child must live at home (that is, did not live in an institution).
3. The child must be chronically ill or disabled for at least 6 months and require more care than a

### Caregivers' Time Costs

personal care (helping with the child's bathing, grooming, eating, and so forth);  
 providing medical care (for example, medications, tube feedings, treat wounds);  
 preparing special or extra meals and cleaning up afterward;  
 extra or special shopping and running errands (for example, buying clothing, picking up medications);  
 extra household chores (cleaning home, snow shoveling, yard work);  
 escorting this child to get health care;  
 escorting this child to nonmedical functions beyond what you would have to do if he or she were healthy (for example, social activities, entertainment);  
 managing this child's medical conditions scheduling appointments with physicians, talking to physicians, nurses, and social workers);  
 managing this child's finances (dealing with insurance companies, finding special programs, filling out forms);  
 waiting in physicians' offices;  
 monitoring medical equipment, cleaning, making sure it is in working order.

NOTE: This list was authored by M. Aroskar, J. Brust, T. Choi, J. Keenan, B. Leonard, and S. Ostwald, University of Minnesota, 1988.

child of the same age without a health problem.

4. The caregiver must be providing care at the time the survey was completed and had provided care for at least 2 months.

5. The caregiver did not receive pay for caregiving (with the exception of foster parents), that is, was not a professional caregiver.

### Materials

Caregivers were asked to complete a 19-page survey designed for this study. The survey, which measures caregiving time and out-of-pocket expenses, included questions adapted from other studies (4-6). The survey also included demographic information on the child and caregiver and medical information on the child. The survey was pretested with 10 mothers of severely disabled children who had met the study's criteria. Based on their suggestions, modifications were made to improve the survey's content and clarity.

SCH mailed surveys and two reminder letters to the subjects to ensure their privacy. Therefore,

information is available only on those who returned a completed survey. Of the 221 surveys mailed, 4 were returned with no forwarding address and 9 were returned because the child did not meet study criteria; 57 were not returned. Therefore, 151 surveys (73 percent) were used in the analysis.

### Measures

**Time.** Caregivers were asked to estimate the time necessary to do additional tasks related to the child's disability. Tasks were narrowly defined, and caregivers were allowed to respond on a daily, weekly, or monthly basis to increase the accuracy of the estimate (7). Tasks were not to be double-counted, and they were not to exceed 24 hours per day. Caregivers' time costs are listed in the box at left.

**Out-of-pocket monthly expenses.** Caregivers were asked to estimate average monthly out-of-pocket expenses (those not covered by Medicaid, insurance, or any other program) related to the care of the disabled child. Out-of-pocket monthly expenses are listed in figure 2.

**Functional dependency.** The functional dependency scale, described in the box on page 308, measures a child's physical "dependency" on a four point Likert-like scale for 10 functions including eating, bathing, grooming, and so forth. The total score is summed and then averaged, with no adjustments made for age. A score of one indicates total independence and four indicates total dependence.

### Sample Description

**Caregivers' characteristics.** Table 1 describes the caregivers of the children in this study. A profile of the primary caregiver is a white, married, 33-year-old mother living in a rural area, having received some college education, and working 12 hours per week with a total household income after taxes of \$19,000 per year.

The number and standard deviation (SD) of the caregivers' ages, hours worked per week, and income follow:

Characteristic	Number	Median	SD	Range
Age (years).....	147	33.0	± 6.7	18-67
Hours worked per week .....	149	12.00	± 20.05	0-60
Income (annual dollars after taxes).....	151	\$18,972	± \$17,910	\$1,729-\$44,697

Figure 2. Out-of-pocket expenses

Your Average Monthly CAREGIVING Costs:	Your Average Monthly CAREGIVING Costs:
1. Transportation	11. Extra garbage to be hauled away
a. helicopters, ambulance	\$ <input style="width: 100px;" type="text"/>
b. rental van, car	12. Substitute care when you are away from the premises
c. parking	\$ <input style="width: 100px;" type="text"/>
d. public transportation (bus, taxi) to get to child's house, run errands, go to child's doctor, hospital, etc.	13. Extra "Eating out"
2. Relocation expenses because the child needs care	\$ <input style="width: 100px;" type="text"/>
(e.g., rent or hotel expenses in order to be near the child who requires care)	14. Insurance
3. Homemaking services	a. additional homeowner's insurance because of the child's medical equipment (or some other liability due to illness)
4. Supplies (e.g. Chux, bandages)	\$ <input style="width: 100px;" type="text"/>
5. Clothing (special and/or additional because of the illness)	b. additional health insurance premiums because of the child's illness/disability
6. Medications	\$ <input style="width: 100px;" type="text"/>
7. Medical, psychological or other therapy costs not covered by insurance	15. Laundry expenses because of providing care
8. Long distance telephone costs	\$ <input style="width: 100px;" type="text"/>
9. Utility increases due to special equipment	16. Special educational needs
10. Special diets (food, formulas)	\$ <input style="width: 100px;" type="text"/>
	17. Other (please specify):
	_____
	_____
	_____
	18. Mileage (i.e. not dollars) for the child's doctor, hospital, or other care visits, to run errands for the child, etc.
	_____ Miles per month
	19. Mileage (i.e. not dollars) to get to the child's home who requires care
	_____ Miles per month

Authorized by: M. Aroskar, J. Brust, T. Choi, J. Kennan, B. Leonard, and S. Ostwald, University of Minnesota

Table 1. Characteristics of 151 caregivers

Category	Number	Percent
<b>Relationship:</b>		
Mothers .....	134	88.7
Fathers .....	15	9.9
Stepmother .....	1	0.7
Grandmother .....	1	0.7
<b>Race:</b>		
White .....	150	99.3
Native American .....	1	0.7
<b>Residence:</b>		
Urban .....	53	35.1
Rural .....	98	64.9
<b>Marital status:</b>		
Single, never married .....	2	1.3
Married .....	134	88.8
Separated, divorced, widowed .....	15	10.0
<b>Education:</b>		
Less than high school .....	7	4.6
High school graduate .....	55	36.4
Some college .....	64	42.3
College graduate .....	25	16.6
<b>Employment:</b>		
Employed 10 hours week or more .....	80	53.7
Unemployed or less than 10 hours per week .....	69	46.3

**Disabled children's characteristics.** The descriptive data on the children in this study can be found on table 2. Interestingly, 45 percent of the disabled children were categorized as technology dependent according to the Office of Technology Assessment's definition (5). According to that definition, technology dependent children depend on a "medical technology that compensates for the loss of normal use of a vital body function and who require substantial daily skilled nursing care to avert death or further disability" (5a). Examples of dependence on medical technology include dependence on a ventilator, intravenous therapy, and nutritional support (5). These children had a median functional status score of 2.3.

A demographic profile of these children is a 6-year-old Caucasian boy with siblings, having one of three primary diagnoses—spina bifida, cerebral palsy, or cystic fibrosis—and he is likely to need assistance with activities of daily living.

The median and SD of the children's age, number of siblings, and score on the Functional Dependency Index follow:

Characteristics	Number	Median	SD	Range
Age (years) .....	148	6.0	± 4.3	1-17
Number of siblings ..	151	1	± 1.20	0-5
Functional Dependency Index <sup>1</sup> .....	151	2.30	± .77	1.00-3.67

<sup>1</sup>1 = independence and 4 = dependence.

**Home care characteristics.** Formal paid assistance (for example, nurses, home health aides) was received in 21 percent of the homes (table 3). Informal assistance (for example, family, friends, neighbors) was received by 93 percent of the caregivers with most of this help coming from the immediate family—the child's mother, father, grandmother, and sister. Eleven of 151 respondents (7 percent) stated they received no help in caregiving. Most families had their medical expenses covered by private insurance (53 percent), yet 15 percent had neither private insurance nor Medicaid.

Daily time involvement by the primary caregiver for child care of the severely disabled child ranged from 0-20 hours with a median of 4 hours and 42 minutes. The average monthly out-of-pocket expenses ranged from \$0-\$1,240 with a median of \$193.

### Data Procedures

All survey instruments were reviewed for face validity. Because three of the respondents had exceedingly high out-of-pocket expenses (exceeding \$1,240 per month), they were eliminated from the analysis. Income data obtained from completed Internal Revenue Service 1040 tax forms produced three families with large negative income figures from farm or other business losses. These three were also eliminated from the analysis. Finally, two respondents claiming weekly employment hours in excess of 70 hours were eliminated from the analysis.

### Analysis

Stepwise discriminant analysis (DA) was used to select those combinations of variables that best predicted membership in the high or low group for caregiving time and monetary expense. Thirteen independent variables were initially included in the analyses (fig. 1). Nine variables for out-of-pocket expenses and seven variables for time were found to have very insignificant contributions to the variability. The competition of each independent variable for contribution to each of the dependent variables is summarized in tables 4 and 5 for each inferential analysis. The initial sample included 151 respondents. The sample was reduced to 143 for the inferential analyses by excluding outlying cases as reported before.

To use discriminant analysis, the dependent variables, monthly out-of-pocket expense and daily time involvement, were broken into two groups,

high and low. The resulting dichotomous values were

<i>Expenses</i>	<i>Observations</i>
Out-of-pocket:	
Group 1: less than \$100 per month .....	49
Group 2: greater than \$300 per month .....	39
Total .....	88
Time:	
Group 1: less than 3 hours per day .....	49
Group 2: more than 7 hours per day .....	44
Total .....	93

Groups were separated to concentrate on the extreme variability. This was accomplished by having approximately equal observations in the high and low groups and excluding one-third of the observations in the middle group.

## Results

**Out-of-pocket expenses.** Table 4 lists the variable coefficients, discriminant equation, and group centroids of the DA analysis of expenses. The ability of the DA model to predict group membership for the dependent variable, monthly out-of-pocket expenses, is affected by these relationships: monthly out-of-pocket expenses increase when the child's daily time care needs increase, when technology dependence is present, when there is private insurance, and when the child has spina bifida. These four variables account for 32 percent of the variability in out-of-pocket expenses.

The discriminant function for monthly out-of-pocket expenses predicts with approximately 72 percent accuracy into which group the families can be classified by using the set of independent variables listed. The expected rate would be 50 percent. In other words, knowing a family's status on these variables, one can correctly classify them for monthly expenses—low (\$100 or less) or high (\$300 or more).

**Time.** Table 5 lists the variable coefficients, discriminant equation, and group centroids of the DA of caregiving time. The ability of this model to predict group membership for the dependent variable, time, is assisted by six relationships: caregiving time increases as out-of-pocket expenses increase, as the functional dependency of the child increases, with the presence of Medicaid, and with the presence of technology dependence. Caregiving time decreases with the presence of spina bifida as the primary diagnosis and as the hours worked per week by the caregiver increases. These six variables ex-

Table 2. Characteristics of 151 severely disabled children

<i>Category</i>	<i>Number</i>	<i>Percent</i>
<b>Sex:</b>		
Male .....	90	60.0
Female .....	61	40.0
<b>Race:</b>		
White .....	142	94.0
Asian .....	1	0.7
Native American .....	1	0.7
Unknown .....	7	4.6
<b>Siblings or other children:</b>		
None .....	34	22.5
One .....	50	33.1
Two .....	40	26.5
Three or more .....	27	17.9
<b>Major diagnosis:</b>		
Cerebral palsy .....	39	25.8
Cystic fibrosis .....	21	13.9
Spina bifida .....	20	13.2
Other <sup>1</sup> .....	68	45.0
Unknown .....	3	2.0
<b>Technology-dependence:</b>		
No .....	83	55.0
Yes .....	68	45.0

<sup>1</sup> Cancer, heart disease, respiratory, and nervous system disorders.

plain 38 percent of the variability for daily time demands.

The discriminant function for caregiving time indicates that there is a good ability to predict into which group families can be classified by using the set of independent variables listed. With an expected rate of 50 percent, the DA model has a 77 percent ability to correctly classify that the amount of caregiving time will be low (3 hours per day or fewer) or high (7 hours per day or more).

## Discussion

Families in this study reported caregiving time for the disabled child at 4 hours and 42 minutes per day (median). This time includes time spent on tasks such as feeding, bathing, and grooming the child, as well as time spent taking the child to the physician and filling out medical forms. Families also report monthly out-of-pocket expenses at \$193 (median) or 12.5 percent of their income.

Because no other study has estimated caregiving time in this manner, there are no comparisons for these estimates. However, with close to half of the children in the sample dependent on medical technology to sustain their lives, a large demand is highly probable. The estimate that out-of-pocket expenses consume 12.2 percent of the families' income is comparable to another study's (8) estimate that the financial burden for severely disabled

## Functional Dependency Scale

<i>Score</i>	<i>Function</i>	<i>Score</i>	<i>Function</i>
	<b>Dressing</b>		<b>Walking</b> (answer in terms of person's physical ability to walk)
1	dresses without help of any kind,	1	walks without help of any kind,
2	needs and receives supervision (such as receives assistance to lay out clothes, fasten clothing),	2	needs and receives the help of a device (braces, walker, or crutch[es]),
3	needs and receives help from another person to put on clothing,	3	needs and receives the personal help of one or more persons,
4	is dressed (unable to participate).	4	unable to walk.
	<b>Grooming</b>		<b>Orientation</b> (refers to a child's awareness of his or her present environment in relation to time, place, and person),
1	grooms self without help or supervision,	1	oriented,
2	needs and receives supervision,	2	partial or intermittent periods of disorientation,
3	needs and receives daily help from another person,	3	totally disoriented; does not know time, place, identity,
4	is groomed (unable to participate).	4	comatose.
	<b>Bathing</b>		<b>Communication</b>
1	bathes without help of any kind,	1	communicates needs verbally without difficulty,
2	needs and receives supervision only,	2	communicates needs verbally with difficulty but can be understood,
3	needs and receives personal help washing and drying body,	3	communicates needs with sign language, symbol board, written messages, gestures, or interpreter,
4	is bathed (unable to participate).	4	unable to communicate needs.
	<b>Eating</b>		<b>Hearing</b> (with hearing aid, if customarily worn)
1	eats without help of any kind,	1	no hearing impairment (or corrected to normal),
2	eats with minimal help or supervision (for example, needs help to cut meat, butter bread),	2	hearing difficulty at level of conversation,
3	needs and receives partial assistance with eating from another person,	3	hears only very loud sounds,
4	needs and receives total feeding from another person, tube feeding, or intravenous feeding.	4	no useful hearing.
	<b>Toileting</b>		<b>Vision</b> (with corrective lenses, if customarily worn)
1	independent, manages minor problems by self, or manages care of ostomy or catheter without assistance,	1	no impairment of vision (or corrected with glasses or contacts),
2	is continent (is able to control own bowel and bladder) but needs minor assistance or supervision (for example, with wiping),	2	partial impairment (for example, can read large print only, poor night vision),
3	occasional incontinence, (occasionally cannot control either bladder or bowel),	3	substantial impairment (for example, cannot read, cannot drive, cannot see large objects),
4	is incontinent (cannot control bowel and bladder).	4	no useful vision.

NOTE: This scale was revised by M. Aroskar, J. Brust, T. Choi, J. Keenan, B. Leonard, and S. Oswald, School of Public Health, University of Minnesota, 1988.

children possibly exceeds 10 percent of the families' income.

It should be noted that fully 15 percent of this sample's families did not have medical care expenses covered by insurance or Medicaid. According to Butler and coworkers (1), 10.3 percent of all children with functional limitations have no insur-

ance coverage, and among low-income children with disabilities, fully 19.5 percent have no coverage.

Families in this sample have medium to low incomes (income is part of the eligibility process for the SCH program), and their lack of medical care coverage falls within the estimates of Butler and coworkers (1). They estimated that 60 percent

of disabled children are covered by private insurance (53 percent in our sample), and Medicaid coverage ranged from 10.4–51.2 percent, depending on the State. In our sample, 10 percent of the children received Medicaid; however, another 22 percent received a combination of Medicaid and private insurance support, again falling within the estimates of Butler and coworkers.

Their estimates, however, are based on data collected in 1979, and in the 1980s the Federal Government attempted to expand Medicaid coverage for the severely disabled through such programs as model waivers and Tax Equity and Fiscal Responsibility Act, section 134. These expansions have not provided coverage for all who request assistance, as evidenced by waiting lists for various Medicaid Programs (9). Indeed, using data from 1986, the Office of Technology Assessment estimated that 14–19 percent of all children between ages 0–12 years were without health insurance (10).

As Butler and coworkers have shown, disabled, poor children have even lower levels of insurance coverage. It is not surprising, therefore, that although the level of disability reflected by disease categories, functional dependency scores, and dependence on technology was fairly high, only 21 percent of our families received paid help (for example, nurses, home health aides) that would be third-party reimbursed services.

The analyses of those with high and low out-of-pocket expenses and caregiving time demands indicate several important findings: increased time demands are associated with increased out-of-pocket expenses, that the child's increased disability as measured by functional dependency and technology dependence increases caregiving time and out-of-pocket expenses, that the hours worked by the caregiver decreases the hours spent caregiving, and that having private insurance increases out-of-pocket expenses and having Medicaid increases caregiving time. Additionally, parents who have a child with spina bifida have decreased time costs but increased out-of-pocket expenses. These associations are strong enough to predict 72 and 77 percent of those in the high or low groups for out-of-pocket expenses and time demands.

**Distribution of resources versus access to resources.** Administrators and policymakers should be sensitive to the observations of this study: caregiving resources have not been distributed equitably across families. This model indicates that families caring for the most severely disabled children have greater out-of-pocket expenses and time burden and that

Table 3. Characteristics of home care environment, 151 respondents

Category	Number	Percent
Formal help (for example, nurses, home health aides) .....	32	21.2
Informal help (relatives, friends):		
Mother .....	13 of 17	76.5
Father .....	121 of 136	89.0
Sister .....	32 of 151	21.2
Brother .....	28 of 151	18.5
Grandmother .....	39 of 150	26.0
Grandfather .....	25 of 151	16.6
Aunt .....	16 of 151	10.6
Uncle .....	6 of 151	4.0
Friends .....	21 of 151	13.9
Neighbors .....	9 of 151	6.0
No help .....	11	7.3
Reimbursement-payment for medical expenses:		
Private insurance .....	80	53
Medicaid .....	15	10
Private and Medicaid .....	33	22
No Medicaid or private insurance ..	25	15
Daily time (hours per day) <sup>1</sup> .....	151	...
Monthly expenses (dollars per month) <sup>2</sup> .....	148	...

<sup>1</sup> Median = 4.7 hours, SD = ± 4.56, range 0–20.

<sup>2</sup> Median = \$193, SD = ± \$381, range \$0–\$1,240.

resources have not kept up with the overall financial burden.

This study indicates that significant burdens, which the most severely disabled child places upon the family, transcends urban and rural boundaries, household size, and income levels. Therefore, distribution of resources to at-risk families should not be targeted at families with specific demographic profiles. Instead, the distribution should be targeted at the status of the child. How ill is the child? What are the total resources required by the child? What is the most cost-effective means to meet those resource needs and lower the overall financial burden on the family?

While current legislation is aimed at providing equal access to services and resources, the issue of distribution should not be overlooked. If the proposals before State legislatures regarding Medicaid Model Waivers or regulation of private insurance are to be effective, they must recognize the discrepancies of time and expenses when caring for children whose disabilities vary in severity.

**Nonsubstitutability of time and money.** It was assumed that time could be substituted for money (and vice versa) in the care of the severely disabled child. The rationale was that caregivers who pro-



Table 4. Stepwise discriminant analysis of monthly out-of-pocket expenses for 4 independent variables, 88 respondents

Step	Independent variable	Standardized coefficient	Wilks' lambda <sup>1</sup>	Change: Wilks' lambda	P value
1.	Daily time . . . . .	.82236	.78225	.21795	.0000
2.	Technology dependence . . . . .	.46067	.73319	.04906	.0067
3.	Private insurance. . . . .	.35784	.71072	.02470	.0542
4.	Spina bifida. . . . .	.33839	<sup>2</sup> .68739	.02730	.0427

<sup>1</sup> Wilks' lambda is the complement of R<sup>2</sup> and is used to measure the unexplained variance in discriminant scores calculated from the equation.

<sup>2</sup> P value < .0001.

NOTE: Discriminant equation: discriminant analysis = monthly out-of-pocket expenses = -2.17 + .20 (daily time) + .96 (technology dependence) + .79 private insurance + 1.05 spina bifida.

Group centroids: Group      Group centroids  
 ≤\$100                      - .59475  
 >\$300                      .74725

Table 5. Stepwise discriminant analysis of daily time for 6 independent variables, 93 respondents

Step	Independent variables	Standardized coefficient	Wilks' lambda	Change: Wilks' lambda	P value
1.	Monthly expenses . . . . .	.55816	.86977	.13023	.0002
2.	Functional dependency . . . . .	.51102	.77129	.09480	.0003
3.	Medicaid . . . . .	.37793	.71444	.03431	.0022
4.	Technology dependence . . . . .	.41579	.68013	.03431	.0112
5.	Spina bifida. . . . .	-.39495	.64454	.01771	.0066
6.	Hours worked per week . . . . .	-.27956	<sup>1</sup> .62683	.03559	.0458

<sup>1</sup> P value < .00005.

NOTE: Discriminant equation: discriminant analysis of daily hours of care = -2.40 + .70 (functional dependency) + .85 (technology dependence) - .15 (hours worked per week) + .86 (Medicaid) - 1.24 (spina bifida) + .0023 (monthly expenses).

Group centroids: Group      Group centroids  
 ≤3 hours                      - .72324  
 >7 hours                      .80542

vide more direct care for their child would have fewer out-of-pocket expenses. In 1987, the Office of Technology Assessment advanced this assumption in the report "Technology Dependent Children: Hospitals vs. Home Care"(5). The measurement and substitution of time costs, or "the ability and willingness of family members to provide ongoing nursing care for a substantial part of the day," are important factors in containing costs at home and within the health care system (5). However, in this model, time did not substitute for out-of-pocket expenses, and in fact, monthly expenses and daily time were significantly correlated in a positive direction. Severity of disability and the use of family and public resources appear to drive this relationship.

If the analyses are considered in a conjoined fashion, the variables that explain the daily time

involvement can be substituted in the equation that explains the monthly expenses. This indicates that the opportunity cost of caring for a child who suffers from a more severe disease or disabling condition is driving the greater financial burden of the families. Therefore, the financial burden in terms of both time and money is unevenly shared by families of severely disabled children.

**Severity of disability and diagnosis orientation.** The functional dependency score and dependence on technology were significant variables in determining the greater amount of time and out-of-pocket expenses involved in caring for the severely disabled child and in predicting group membership in the discriminant analysis.

Cystic fibrosis, spina bifida, and cerebral palsy were the only diagnoses with enough cases to warrant isolation. They each had better than 13 percent of all observations. Together they accounted for 53 percent of all primary diagnoses. Spina bifida had some predictive value in the model, indicating that out-of-pocket expenses and time may be driven by disease-specific factors. Although the model showed time and out-of-pocket expenses were associated in a positive direction, a child with spina bifida had increased expenses but had decreased caregiving time. This finding illustrates the value of categorizing or specifying diagnoses. The study demonstrated that the isolation of the diagnosis coupled with a severity index could provide a basis for the equitable allocation of funds for the care of a chronically disabled or ill child.

**Income and private insurance as determinants.** Contrary to assumptions, income was not found to be significant in establishing the burden to the families. Income level was not statistically significant in predicting time and out-of-pocket expenses. This may have been partially due to the small spread in incomes in this sample. The assumption was that as the income of the household increases, the financial burden to the caregiver would decrease. This may be true, in a relative sense. However, a study by Newacheck and Halfon (11) found that out-of-pocket medical expenses for children increased in a progressive fashion with family income. Yet when out-of-pocket expenses were measured relative to ability to pay, there was a regressive pattern. This study viewed monthly expenses as an absolute value. Future studies, which access a wider spread of incomes, should also as-

sess the relationship between relative expenditures and ability to pay.

The presence of private insurance to cover part or all of the medical expenses should theoretically reduce the financial burden of the caregiver. However, deductibles, copayments, and limited benefit coverage for support services sometimes force families to forego services or incur large out-of-pocket expenditures for services such as babysitting, day care, and transportation (12). Cabin (13) reports that there are several gaps in private health care:

- Private insurance usually covers hospital, laboratory, and drug costs, but does not cover nonmedical expenses.
- Private insurance often has exclusions from coverage for children with chronic problems.
- Private insurance does not cover most children who have limitations in activity and whose income is below the poverty line:

In this study, families with private insurance had increased out-of-pocket expenses. Thus, private insurance for the severely disabled child belies its purpose; it does not insure that a family will not have large out-of-pocket expenses. Medicaid, however, appeared to protect families from large out-of-pocket expenses but was associated with increased time demands. From this study, it is not possible to assess why Medicaid increased caregiving time. It may be more time is spent securing care, or that fewer services are covered and thus more are done by the parent.

Even wealthy families are not insulated from the commitment of time and money to provide care for a very severely disabled child in the home. Aside from large expenses, wealthier families may absorb more of the actual costs because they have less access to public resources. Many private and public programs screen families based upon income and insurance coverage. Middle class families who carry some private insurance and have inadequate assets to meet the financial needs of caring for their child may also face a financial burden they cannot meet. Families below or near the poverty line are always at risk because they must depend largely upon public funds. A low income coupled with little or no private insurance puts a family at extreme financial risk.

Although this study did not address the issue of psychological burden, excess time and financial demands would make family members susceptible to mental health problems (3,4). The long-term nature, and the relentless state of demands put all

families with disabled children at risk, but especially those with the most severely disabled children.

### Summary

To distribute resources more equitably, Newa-check and McManus (2) suggest “redirecting existing resources, expanding Medicaid coverage, creating risk pools, and developing a national program of catastrophic expense protection” (2a).

Financial burden on the family, as measured by the positively correlated caregiving time and out-of-pocket expenses, is an issue which health care policymakers, administrators, and providers need to address to make home health care operative in an age of cost containment. Using the model established in this preliminary study as a stepping-stone to more precise models can lead to greater systemwide cost savings.

### Recommendations

There is unequal and inequitable access to home health care for severely disabled children. The need to distribute equitably the extraordinary costs of this care among the various private and public payers is paramount. The need to distribute resources equitably to minimize the burden to the caregiving families is equally important. “The object of social policy should be to minimize the total cost, not just the cost of publicly provided services” (14).

Policies aimed at the distribution of resources to reduce expenses to at-risk families should not target families with specific demographic profiles but should instead target the particular status of the child, primarily the disease’s severity as measured by the child’s need for caregiver assistance.

The current approach is modeled on access to financial resources; basically there are greater resources for those who have less private insurance coverage. However, the findings of this study indicate that a future need-based approach should factor the severity level of the child’s disability into the model. This approach would help to solve the problem, which these data reveal—that there is an inequitable burden among families with disabled children, with the most severely disabled children increasing the family burden significantly.

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## The Nutritional Status and Dietary Adequacy of Single Homeless Women and Their Children in Shelters

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### Synopsis .....

*Data were collected on the nutrient intake and nutritional status of 96 single mothers and their 192 dependent children who had been displaced from their homes. The objective of the study was to provide information on the dietary adequacy of a newly identified subgroup of homeless persons, single women and their dependent children.*

*Once situated in temporary housing, those participating in the study indicated that they believed*

*that they were receiving sufficient food. However, a nutrient analysis found that the study subjects in all age groups were consuming less than 50 percent of the 1989 Recommended Dietary Allowances (RDA) for iron, magnesium, zinc, and folic acid. Adults were consuming less than 50 percent of the RDA for calcium. The type and amounts of fats consumed were in higher than desirable quantities for a significant number of subjects of all ages. The health risk factors of iron deficiency anemia, obesity, and hypercholesterolemia were prevalent.*

*The findings indicate a need to examine and remedy nutrient intake deficiencies among single women who are heads of household and their dependent children in temporary housing situations. Diet-related conditions found included low nutrient intakes that may affect child growth and development, risk factors associated with chronic disease, and lack of appropriate foods and knowledge of food preparation methods in shelter situations. Applicable, understandable nutrition education should be offered mothers in shelter situations to help them make food choices at the shelter and when they become self-sufficient. Assistance programs such as the Special Supplemental Food Program for Women, Infants, and Children, and food stamps, should be available to this group.*