

# Childhood Functional Status, Family Stressors, and Psychosocial Adjustment Among School-aged Children With Disabilities in the United States

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**Background:** During the last 30 years, several studies have indicated that children with disabilities are at increased risk for emotional and behavioral morbidity. Population-based studies are needed to understand the relationship between functional status, family stressors, and the psychosocial adjustment of children with disabilities.

**Methods:** Using data from the 1994 and 1995 National Health Interview Surveys, Disability Supplement, this study examines the associations between children's functional status, family stressors, and the psychosocial adjustment of school-aged children with disabilities.

**Results:** Regression analyses indicate that children's func-

tional impairments in the areas of communication or learning, poor maternal health and mental health, family burden, and poverty are significantly and positively associated with psychosocial maladjustment among children with disabilities.

**Conclusions:** Children's functional activity limitations and family stressors are significant correlates of psychosocial adjustment among children with disabilities. These data indicate a need for routine screening for mental health problems among children with disabilities, as well as a family-oriented approach to their medical care.

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**D**URING THE LAST several decades, the decline in childhood mortality and the rise in childhood chronic diseases have resulted in approximately 12.6 million, or 18%, of noninstitutionalized children experiencing a special health care need.<sup>1</sup> Consequently, the medical focus shifted from mere survival to quality of life.<sup>2</sup> Children with special health care needs include those with a chronic medical condition or permanent impairment that is associated with an increased need for health care.<sup>3</sup> Central aspects of quality of life are psychosocial and role functioning, including emotional state, relations with others, independence, and productivity.<sup>4,5</sup> Ensuring and improving the quality of life of children with disabilities necessitates understanding their psychosocial functioning and how it is associated with child, condition, and family characteristics.

Children with disabilities or chronic illnesses have been shown to be at increased risk for psychological morbidity,<sup>6-9</sup> as are their family members.<sup>10,11</sup> In fact, research has indicated that psychological maladjustment is 10% to 15% higher among children with chronic con-

ditions, compared with healthy controls.<sup>12</sup> The Ontario Child Health Study found that children with chronic conditions and major disability were 3 times more likely to have a psychiatric disorder than their healthy counterparts, controlling for age- and sex-specific risks for psychiatric problems.<sup>13</sup>

## DISEASE PARAMETERS

Even though studies show compelling commonalities in the psychosocial problems associated with a range of different childhood disabilities,<sup>14,15</sup> disease parameters are often thought to influence children's psychosocial adjustment. However, most studies show no evidence that disease severity affects adjustment<sup>16</sup>; and with the exception of brain disorders, few studies show that condition type is related to children's psychosocial adjustment.<sup>17</sup> The literature is inconsistent concerning the role of functional status, or the ability to perform everyday tasks appropriate for a particular age,<sup>18,19</sup> in children's psychosocial adjustment; some studies indicate that functional status does affect adjustment,<sup>20,21</sup> whereas others have not found such an association.<sup>22</sup>

## FAMILY STRESSORS

A recent meta-analysis of the correlates of psychological adjustment in youth with physical disorders found that parent, child, and family-related factors were more strongly associated with children's adjustment than disease or disability parameters.<sup>19</sup> In particular, poor family functioning,<sup>12,23</sup> low income,<sup>2</sup> maternal distress,<sup>19</sup> and a significant burden of illness on the family<sup>24</sup> have been individually associated in different studies with children's psychological maladjustment. Moreover, positive family-based characteristics such as parental self-esteem,<sup>25</sup> family social support,<sup>26</sup> the child's coping mechanisms,<sup>27</sup> and health care beliefs<sup>28</sup> all contribute to adaptation and resiliency among children with disabilities or chronic conditions, as well as children without disabilities.<sup>29-33</sup>

### LIMITATIONS OF AVAILABLE RESEARCH

Nearly all of these studies have been conducted on convenience samples of families in a specific geographic area whose children are actively involved in health care services. These factors create sampling biases, potentially limiting the generalizability of such studies.<sup>34</sup> Population-based studies are needed to examine the association of functional status and family factors in the psychological adjustment of children with disabilities.<sup>2,19,23,35</sup>

Moreover, theoretically guided research is needed to provide a comprehensive, systematic, and clinically relevant body of knowledge. An integration of systems theory,<sup>36-39</sup> social-ecological systems theory,<sup>40,41</sup> and stress theory<sup>42,43</sup> predicts that children's development is affected by individual, family, community, and systems-level characteristics and that stress on any person in the family system has a major influence on the health of all family members. Substantial research indicates that disability can be a major life stressor for children and their families.<sup>41,44-46</sup> These models suggest that to understand psychosocial adjustment and the needs of children with disabilities it is necessary to clarify the interconnections between adjustment and their own health status and activity limitations, as well as maternal health and the presence of family stressors.

### CURRENT STUDY

In this study, we used the 1994 and 1995 National Health Interview Surveys (NHIS), Disability Supplement (NHIS-D), to investigate the association between child, maternal, and familial factors and the psychosocial status of children and adolescents, aged 6 to 17 years, with disabilities. Specifically, this study aimed to determine (1) the strength and extent of the association between children's functional status and their psychosocial status and (2) the relationship between adjustment and the following potential family stressors: maternal health, mental health, and activity limitations, family burdens resulting from the child's disability, poverty status, and single-parent household status. We hypothesized that limitations in children's functional activities and each of the family stressors will be associated with poor psychoso-

cial adjustment among school-aged children with disabilities.

## METHODS

Data are from the 1994 and 1995 NHIS-D. The NHIS is a household survey conducted by the National Center for Health Statistics. The multistage, stratified probability design of the NHIS yields national estimates for the civilian, noninstitutionalized US population. The population estimates presented here are based on the averaged weights for 1994 and 1995, so as to yield more accurate overall estimates.<sup>47</sup>

Disability, especially childhood disability, was one of the special health topics assessed for 2 consecutive years in the 1994 and 1995 NHIS. The NHIS-D consisted of 2 phases, and data collection was accomplished by interviewers who were employed and trained by the US Census Bureau. Phase I included disability-related questions asked of all household members in the NHIS Core and served as a screener for phase II, the NHIS-D. Interviewing for phase II started in August 1994 and was completed in 1997.

### STUDY POPULATION

Children were selected for this study if they were aged 6 to 17 years and living in a primary household (ie, a household in which only 1 family resides) and their biological mother was listed as the survey respondent. Biological mothers were respondents for 71.8% of children with disabilities and 66.5% of children without disabilities.

#### Linkage of Children to Their Mothers

Mother-child dyads were created by linking the personal identification number of the biological mother with that of the child. For 13% of these children, although the mother responded, she was not identified through the personal identification number on the survey, so her personal record could not be definitively matched to the child's. In these cases, the child was linked to the oldest woman between the ages of 18 and 56 years living in the child's household, in order to identify the mother. This method was shown to produce a highly accurate linkage.<sup>48</sup>

#### Definition of Children With Disabilities in the NHIS-D

The National Center for Health Statistics identified children as having a disability by using questions from the NHIS Core and the NHIS-D, which covered limitations of activity, impairments (ie, visual, hearing, and mobility), activities of daily living, specific developmental disabilities, special health needs, and special education services.<sup>49</sup> From these sets of questions, "disability hit flags" were constructed, and children with 2 or more flags and some single flags were classified as having a disability. For example, children and adolescents would be considered to have a disability if their mother reported that a chronic physical, cognitive, behavioral, or psychological condition(s) or impairment(s) affected their ability to participate in the type or amount of life activities appropriate for their age group.<sup>49,50</sup> For children in our sample, aged 6 to 17 years, their life activity was attending and participating in school. Chronic conditions were conditions that lasted for more than 3 months or specific conditions or diagnoses that were identified as chronic, irrespective of duration, such as mental retardation. This definition was recently shown to be highly comparable to other definitions used to identify children with special health care needs in the NHIS.<sup>51</sup> Parents of children who met these criteria in the 1994 and 1995 NHIS-D were then reinterviewed.

## Exclusion of Children With Psychiatric Disabilities Only

Nearly 11% of the sample ( $n=407$ ) was described by their mother as having an Axis I psychiatric disorder<sup>52</sup> and no other type of condition. These youth had lower (worse) scores on the Personal Adjustment and Role Skills Scale III (PARS) than disabled youth who had only nonpsychiatric disorders ( $t=11.0$ ;  $P<.001$ ). However, their psychosocial adjustment was not different from those who had both types of disorders ( $t=-1.0$ ;  $P=.33$ ). Children with only Axis I disorders were excluded from all further analyses in order to conduct a more conservative test of the association between disability-related parameters and psychosocial adjustment. Youth with psychiatric disorders in addition to other types of disorders (eg, physical or cognitive) were retained in the disabled sample. We note that children may have been selected for the disabled sample because of an activity limitation caused by an undiagnosed psychiatric disorder. However, because such cases were not identified as having a specific psychiatric condition, they could not be systematically excluded from the sample.

This resulting study sample is based on 3362 children for whom phase II interviews were completed. Among those children who were excluded for nonresponse ( $n=385$ ), most of them children ( $\geq 17$  years) or their proxy respondent either could not be located, refused, or for some unknown reason were unable to conduct the interview.

## MEASURES

### Sociodemographic Characteristics of Child and Mother

The mother provided information about the child's sex, age (6-10, 11-14, and 15-17 years), and race/ethnicity (white non-Hispanic, black non-Hispanic, other non-Hispanic, and Hispanic); maternal education (some high school, high school graduate, some college, and college graduate or beyond), work status (employed or not), marital status (married, widowed, divorced, separated, and never married), and poverty status. Poverty was defined according to the 1994 and 1995 NHIS Poverty Threshold definition. Cutoff points are based on estimates of the 1994 poverty threshold (for the 1995 NHIS file) that were published by the Census Bureau in August 1995; estimates were made by inflating the 1993 threshold by the consumer price index for 1993 through 1994. In the regression analyses, marital status was collapsed into 2 categories: single-parent household (included mothers who were married but their spouse was not living in the household, widowed, divorced, separated, or never married) vs mothers who reported being married with their spouse living in the household.

### Child Health

Mothers rated their child's health as excellent, very good, good, fair, or poor. A dichotomous variable was used in the analyses, comparing children in fair or poor health with children with excellent, very good, or good health.

Activity limitation was measured with a scale constructed and validated by Hogan et al<sup>53</sup> using variables from the 1994 NHIS-D that are related to 4 domains of functional activities in children: (1) moving around inside the home; (2) bathing, dressing, eating, and using the toilet themselves; (3) communicating needs and understanding questions; and (4) paying attention, understanding materials, and controlling one's behavior in school (mobility, self-care, and communication during the last 12 months and learning ability and school-related behavior during the last 2 weeks). Hogan et al identified, constructed, and substantiated these domains based on previous research with severely disabled populations<sup>54-56</sup> and a functional independence measure for

children (WeeFIM).<sup>54,57-59</sup> In the validation study of these domains, the scales resulted in a Cronbach  $\alpha$  of .87 for mobility, .95 for self-care, .74 for communication, and .86 for learning activities, indicating adequate internal consistency reliability.<sup>54</sup>

For our study, children's activity limitation status was defined with 3 dichotomous variables: limited in communication, learning activities, or self-care or mobility. Self-care and mobility were combined because so few mothers reported these limitations for their children and these domains are highly correlated. Functional limitation was further classified by the number of areas of impairment and by severity: none, mild (reporting difficulty on 1-2 questions in 1 or more domains), and moderate or severe (reporting difficulty on 3 or more questions in 1 or more domains).

### Maternal Health and Mental Health

Mothers were characterized as having any distress or depression if they endorsed any of these items: (1) having a depressive episode lasting at least 2 weeks in the past year, (2) having a manic or manic-depressive episode lasting at least 2 weeks in the past year, or (3) being frequently depressed or anxious in the past 2 weeks. Absence of all 3 was coded as no distress or depression. The measure of maternal distress incorporates both symptoms and self-reported diagnoses, in order to be inclusive of women with inadequate access to mental health care, especially poor and minority women who are less likely to receive a diagnosis.<sup>60</sup> Maternal depressive symptoms, as well as diagnosis of depression, have frequently been associated with children's behavior problems and psychopathology.<sup>61,62</sup> Despite this broad definition of emotional distress, women scoring in the distressed range on our measure were significantly more likely to have received community mental health services or to have taken medication for a mental or emotional problem ( $\chi^2=176.1$ ;  $P<.001$ ) in the past year, attesting to the validity of the measure.

Maternal health status was based on mothers' rating of their health as excellent, very good, good, fair, or poor. A dichotomous variable was used in the analyses, comparing mothers in fair or poor health to mothers reporting excellent, very good, or good health.

Maternal activity limitation status was measured by asking the mother if she had a long-term reduction in her performance of typical kinds and amounts of activities as a result of 1 or more chronic conditions. Major activities for mothers included working or keeping house. Mothers were considered limited if they were unable to perform or limited in the kind or amount of major activities or not limited in a major activity but limited in the kind or amount of other activities.

### Family Burden

Mothers reported on the effect of the child's disability on anyone in the family in 3 areas: work status (6 questions), sleep patterns (1 question), and financial problems (1 question). The work status questions referred to whether such problems ever happened; financial and sleep-related questions referred to the last 12 months. If the mother answered yes to any question, family burden associated with the child's condition was indicated for that area. A reliability analysis of the work-related burden measure yielded a Cronbach  $\alpha$  of .84.

### Dependent Variable: Children's Psychosocial Adjustment

The PARS III<sup>63</sup> was developed to measure the psychosocial adjustment of children with chronic physical illnesses. Many items and constructs in the PARS are similar to those in widely used measures of child psychosocial adjustment, such as the Child Behavior Checklist,<sup>64,65</sup> and PARS scores are highly correlated

**Table 1. Sociodemographic and Health-Related Characteristics of Children Aged 6 to 17 Years With and Without Disabilities\***

	Children With Disabilities (Weighted N = 5089)†	Children Without Disabilities (Weighted N = 24 820)†
<b>Sociodemographic Characteristics</b>		
Sex‡		
Male	58.1	48.9
Female	41.9	51.1
Race/ethnicity‡		
White (non-Hispanic)	69.7	68.0
Black (non-Hispanic)§	17.3	15.0
Other (non-Hispanic)§	2.4	3.5
Hispanic§	10.6	13.5
Age, y‡		
6-10§	41.5	44.4
11-14§	35.2	33.1
15-17	23.4	22.5
<b>Health Status</b>		
Fair/poor health status‡	9.5	1.6
<b>Functional Status</b>		
Overall severity of limitations‡		
No limitation§	44.3	96.3
Mild limitation§	44.2	3.2
Moderate or severe limitations§	11.6	0.5
Type of functional limitation		
Limited functioning in self-care or mobility‡	9.0	0.3
Limited functioning in communication‡	25.4	1.4
Limited functioning in learning‡	49.3	3.0
Multiple functional limitations		
>1 Functional limitation‡	22.7	0.8
<b>Mental Health Status</b>		
Poor psychosocial adjustment (≤73.1 PARS score)	11.1	NA
Problems with		
Peer relations	16.9	NA
Dependency	10.4	NA
Hostility	12.6	NA
Productivity	9.7	NA
Anxiety or depression	12.0	NA
Withdrawal	11.6	NA

Abbreviations: NA, not applicable; PARS, Personal Adjustment and Role Skills Scale III.

\*Children with a psychiatric disability only, with no other physical or cognitive disability, were excluded from the sample in order to conduct a more conservative test of the association between disability-related parameters and psychosocial adjustment. Values are given as the percentage of children.

†Weighted in thousands.

‡ $P < .05$  for overall differences between children with and without disabilities ( $\chi^2$  analyses used to test all differences).

§Statistically significant  $\chi^2$  test for each category of characteristic.

||Data are from the PARS subscales in which a problem is 1 SD below the mean.

with Child Behavior Checklist scores.<sup>66</sup> However, the PARS does not include items assessing physical complaints, overcoming a limitation of prior measures for this population. The 28-item PARS includes 6 subscales: peer relations, dependency, hostility, productivity, anxiety-depression, and withdrawal. Although the PARS is not a diagnostic instrument, the measure discriminated between children who did and did not use mental health services.<sup>67</sup> Children scoring below the recommended cutoff point on the PARS are highly likely to meet criteria for an emotional or behavioral disorder, although the PARS is not sufficiently sensitive to identify all children with disorders.<sup>66</sup>

Total PARS scores were calculated by summing all 28 items, with higher scores indicating better psychosocial adjustment. Items referred to the last 30 days and were coded on a 4-point scale as never or rarely, 4; sometimes, 3; often, 2; or always, 1. The internal consistency, Cronbach  $\alpha$ , for the summary score of the PARS was .88 or higher in previous studies<sup>68</sup> and .92 in

our study. Only reports with at least 70% of PARS items completed were retained (96.3% of all cases). The recommended and commonly used cutoff point to indicate poor psychosocial adjustment was 1 SD below the group mean.<sup>69</sup> Thus, based on the group mean (SD) for the current sample of 90.3 (17.2), children were classified as well adjusted (score of more than 73.1; 89% of the sample) or having poor psychosocial adjustment (score of 73.1 or less; 11% of the sample). (The distribution of PARS scores was skewed in this sample; fewer children were classified as maladjusted than would be the case if scores were normally distributed.) Cutoff points were established in the same manner for each subscale. Mean scores for this sample were similar to those reported for community populations of chronically ill youth<sup>68</sup> but higher than those used in clinical studies,<sup>66</sup> in which children tend to be more psychosocially disturbed. This mean score difference reflects the sampling bias of clinical research and does not reduce the validity of this study.

**Table 2. Sociodemographic and Health-Related Characteristics of Families of Children With and Without Disabilities\***

	Children With Disabilities (Weighted N = 5089)†	Children Without Disabilities (Weighted N = 24 820)†
<b>Mother's Sociodemographic Characteristics</b>		
Marital status‡		
Married, spouse in household§	65.2	74.4
Married, spouse not in household	1.6	1.2
Widowed	2.0	1.6
Divorced§	14.3	11.4
Separated§	8.2	5.4
Never married§	8.8	6.1
Education‡		
Some high school§	20.1	16.5
High school graduate	38.9	38.9
Some college	24.9	24.2
College graduate or higher§	16.1	20.4
Not in labor force‡	34.0	32.2
Below the poverty threshold‡	27.0	18.8
<b>Mother's Health and Mental Health Status</b>		
Distressed or depressed‡	17.6	6.5
Fair/or poor health status‡	18.2	9.0
Has an activity limitation‡	22.1	11.2
<b>Family Characteristics</b>		
Burden of child's disability on family		
Work-related family burden	19.3	NA
Sleep-related family burden	5.0	NA
Financially related family burden	4.3	NA
Any burden	21.6	NA

Abbreviation: NA, not applicable.

\*Children with a psychiatric disability only, with no other physical or cognitive disability, were excluded from the sample in order to conduct a more conservative test of the association between disability-related parameters and psychosocial adjustment. Values are given as the percentage of subjects.

†Weighted in thousands.

‡ $P < .05$  for differences between children with and without disabilities ( $\chi^2$  analyses used to test all differences).

§Statistically significant  $\chi^2$  test for each category of characteristic.

## DATA ANALYSIS

Analyses were conducted using SUDAAN (Research Triangle Institute, Research Triangle Park, NC) to correct for the effects on tests of statistical significance of the complex sample design of the NHIS.<sup>70</sup> These sampling methods included clustering within the year of administration, strata, and primary sampling unit and the clustering of children within a household.

We used  $\chi^2$  analyses to test for differences in sociodemographic and health-related characteristics between children with and without a disability. We calculated the least squares means in a linear regression model to examine mean differences in PARS scores across the independent and control variables. Based on these analyses, generalized logit models were fit using generalized estimating equations<sup>71,72</sup> to identify the factors that were associated with child psychosocial maladjustment, while adjusting for the intracluster correlations. Variables related to the child's functional status were entered first, then stressors were entered into the model all at once, and finally variables representing the child's age, race, and sex were added to the model.

## RESULTS

### DESCRIPTIVE ANALYSIS

The first set of analyses compares children with and without disabilities on key child, maternal, and family characteristics. Children with disabilities were more likely to

be male, black (non-Hispanic), and aged 11 to 14 years, compared with other children (**Table 1**).

Children with disabilities were more likely to be in poor health, have activity limitations, and have all 3 types of functional limitations. Although fewer than 1% of children without disabilities experienced more than 1 functional limitation, 22.7% of children with disabilities did (Table 1).

Using the 1-SD cutoff point on the PARS, approximately 11.1% of this sample of children with disabilities experienced poor psychosocial adjustment. The most common psychosocial problems identified on the subscales were peer relations (16.9%) and hostility (12.6%).

Mothers of children with disabilities were more likely to be divorced, separated, or never married, have attained lower levels of education, and not be in the labor force compared with mothers of children without disabilities. These mothers also had significantly higher rates of fair or poor health, activity limitations, and distress or depression, compared with the mothers of children without disabilities (**Table 2**).

More than 21% of families with a disabled child experienced a work, sleep, and/or financial burden as a result of the child's disability, with work-related burdens being most common (19.3%). Families of disabled children were also more likely to have incomes below the poverty threshold (Table 2).

**Table 3. Child Psychosocial Adjustment (PARS Scores)\* by Child's Functional Status or Sex, Poverty, Maternal Distress or Depression, and Family Burden†**

	Mean, Yes/No
<b>Main Stressors</b>	
Child fair or poor health status	89.6/90.5
Child's functional status	
Limited functioning in self-care or mobility	89.7/90.5
Limited functioning in communication	87.4/91.4‡
Limited functioning in learning	87.3/93.4‡
Maternal distress or depression	88.1/90.9‡
Maternal fair or poor health status	89.2/90.7
Maternal activity limitation	88.9/90.6
Burden of child's disability on family	
Work-related family burden	86.2/91.5‡
Sleep-related family burden	83.9/89.7‡
Financially related family burden	85.0/90.7‡
Single-parent status	90.6/90.1
Below the poverty threshold	89.3/90.8‡
<b>Control Variables</b>	
Sex, male/female	90.0/91.0‡
Child's age, y	
6-10§	89.3
11-14	90.4‡
15-17	92.5‡
Race/ethnicity	
White (non-Hispanic)§	90.9
Black (non-Hispanic)	89.2‡
Other (non-Hispanic)	90.1
Hispanic	89.3‡

Abbreviation: PARS, Personal Adjustment and Role Skills Scale III.

\*A higher PARS score indicates better psychosocial adjustment. The mean (SD) PARS score was 90.3 (17.2).

†Children with a psychiatric disability only, with no other physical or cognitive disability, were excluded from the sample in order to conduct a more conservative test of the association between disability-related parameters and psychosocial adjustment. Multiple linear regression was performed in which the PARS score was the dependent variable and all other variables were entered into the model simultaneously ( $R^2 = 0.27$ ).

‡Mean differences  $P < .05$ .

§Reference category.

The remaining analyses, examining PARS scores as a function of child, maternal, and family characteristics, were conducted for disabled children only. Children with communication or learning impairments had poorer psychosocial adjustment. However, children with self-care or mobility problems did not significantly differ in their adjustment scores compared with disabled children without such problems. As predicted, children of mothers experiencing distress and/or depression had worse psychosocial functioning than disabled children of mothers who did not have distress or depression. The presence of work, sleep, and financial burdens on the family was also associated with worse adjustment among children. As is presented in **Table 3**, younger, male, and impoverished children had lower scores on the PARS, indicating more maladjustment.

#### LOGISTIC REGRESSION ANALYSIS

In the final set of analyses, logistic regression was used to examine factors associated with PARS scores below the cutoff point, using all child, maternal, and family fac-

tors. In model 1, poor adjustment was significantly related to child health status and each type of functional limitation, although limitations in mobility or self-care had only borderline significance ( $P = .06$ ) (**Table 4**). When family stressors were added in model 2, the effects of child health status and limited mobility or self-care were no longer significant. Effects for limitations in communication and learning did not significantly change, and maternal distress or depression, maternal health status, every type of family burden, and poverty status were all significantly associated with the increased likelihood of maladjustment among children. The addition of controls for sociodemographic factors in model 3 did not change these relationships.

The odds ratios in the final model indicate that children with limitations in learning and communication were more than 4 and 1.6 times, respectively, as likely to experience maladjustment than disabled children without these limitations. Mothers with poor health and distress or depression were more likely to have a child who was maladjusted, with increases of 70% and 90%, respectively. When mothers reported that the child's disability caused a work-, sleep-, or financially related family burden, children were more than 2 times as likely to have poor psychosocial adjustment. Impoverished children with disabilities were 1.8 times as likely to experience maladjustment compared with children living above the poverty threshold.

#### COMMENT

As predicted, child functional status and family stressors were related to psychosocial maladjustment in this nationally representative sample of children with disabilities. Children with learning and communication impairments were significantly more likely to experience poor psychosocial adjustment; however, self-care and mobility impairments did not increase the chance that a child would be maladjusted. Among the family stressors, family burdens were the strongest correlates of maladjustment in children with disabilities, although poor maternal health or mental health and poverty also were significantly associated.

To our knowledge, this is the first US population-based study to examine these factors and supports much clinical research in which children with disabilities are at an increased risk for psychological morbidity, particularly when they have specific functional limitations and family stressors.<sup>2,19,35,73,74</sup> This study clarifies that physical limitations in themselves are not detrimental to psychosocial adjustment.

Our findings are consistent with prior research indicating that children with conditions that limit brain-related activities of learning and communication are more likely to have behavioral problems than are children with physical disabilities.<sup>75</sup> A simple dichotomous measure of functional status, may, as others have suggested, be a better predictor of psychosocial adjustment than other disease-related parameters.<sup>17</sup>

Many mothers of disabled children are coping with their own health-related limitations, an additional stressor in these families. Nearly one quarter of the families reported substantial work-, financial-, or sleep-related prob-

**Table 4. Binary Logistic Regression Model: Odds of Poor Psychosocial Adjustment\* Among Children With Disabilities†**

	Odds Ratio (95% Confidence Interval)		
	Model 1	Model 2	Full Model
<b>Main Stressors</b>			
Child fair or poor health status	1.8 (1.3-2.6)‡	0.9 (0.6-1.4)	0.9 (0.6-1.4)
Child's functional status			
Limited functioning in self-care or mobility§	1.5 (1.0-2.2)**	1.2 (0.7-1.8)	1.1 (0.7-1.7)
Limited functioning in communication§	1.8 (1.4-2.5)‡	1.6 (1.2-2.1)‡	1.6 (1.2-2.1)‡
Limited functioning in learning§	5.1 (3.7-7.2)‡	4.3 (3.0-6.0)‡	4.4 (3.1-6.3)‡
Maternal distress or depression§	NA	1.8 (1.3-2.6)‡	1.9 (1.3-2.7)‡
Maternal fair or poor health status	NA	1.7 (1.1-2.4)‡	1.7 (1.2-2.5)‡
Maternal activity limitation		1.0 (0.7-1.5)	1.1 (0.7-1.6)
Burden of child's chronic condition on family			
Work-related family burden	NA	2.4 (1.7-3.3)‡	2.3 (1.7-3.2)‡
Sleep-related family burden	NA	2.1 (1.3-3.5)‡	2.2 (1.3-3.6)‡
Financially related family burden	NA	2.3 (1.3-4.0)‡	2.5 (1.4-4.4)‡
Below the poverty threshold§	NA	1.9 (1.3-2.7)‡	1.8 (1.3-2.6)‡
Single-parent status§	NA	0.9 (0.6-1.3)	0.9 (0.6-1.3)
<b>Control Variables</b>			
Sex	NA	NA	0.9 (0.7-1.3)
Child's age, y¶			
11-14	NA	NA	0.8 (0.6-1.1)
15-17	NA	NA	0.5 (0.4-0.8)‡
Child's race/ethnicity#			
Black (non-Hispanic)	NA	NA	0.9 (0.6-1.4)
Other (non-Hispanic)	NA	NA	0.6 (0.2-2.0)
Hispanic	NA	NA	1.0 (0.6-1.7)

Abbreviations: NA, not applicable; PARS, Personal Adjustment and Role Skills Scale III.

\*Odds of having a PARS score  $\leq 73.1$  (1 SD below the mean, 90.3).

†Children with a psychiatric disability only, with no other physical or cognitive disability, were excluded from the sample in order to conduct a more conservative test of the association between disability-related parameters and psychosocial adjustment.

‡Statistically significant ( $P < .05$ ).

§Yes = 1.

||Male = 1.

¶Reference category is age 6 to 10 years.

#Reference category is white (non-Hispanic).

\*\* $P = .06$ .

lems as a result of the child's condition. Importantly, the association between family burden and children's poor psychosocial adjustment remained even after controlling for circumstances that exacerbate these problems, such as poverty and living in a single-parent household. This study supports prior research that has found "family" factors more predictive of the psychosocial adjustment of children with disabilities than the condition parameters themselves.<sup>19,35</sup> Indeed, only limitation in learning was more strongly associated with maladjustment than each of the family burdens.

Several limitations of this study should be considered. First, data are based solely on maternal reports, which although often the best source of information about the child and family may be influenced by the mother's own distress. Second, the PARS is a measure of behavioral and emotional symptoms, does not provide psychiatric diagnoses,<sup>66</sup> and has not been standardized on a representative sample of disabled youth. It is likely that the "maladjusted" group in this study is less distressed and dysfunctional than youth in clinic-based studies using the PARS where the mean score is lower (worse).<sup>66,68</sup> Third, the measures of maternal distress and depression in the NHIS-D do not parallel diagnostic criteria used to identify depression in clinical settings,

although a range of studies has shown that this type of assessment predicts maternal health services use<sup>76</sup> and long-term outcomes of offspring.<sup>77</sup> Fourth, the cross-sectional nature of these data preclude us from examining the direction of causality between the child's psychosocial adjustment and the mother's mental health status or between the child's adjustment and the family's burden.

This population-based study demonstrates that childhood disability affects, and is affected by, the entire family. It strongly suggests the need to support the health and mental care needs of all members of the family in order to foster good mental health in children with disabilities. This deceptively simple statement goes beyond addressing the needs of the family, so they can provide optimal care for their child with special needs. Such supports are indeed indicated<sup>78,79</sup> and are more critical in some families than in others. The complex interrelationship of functional limitations, family burdens, and mothers' and children's mental health and health are associated with a number of modifiable family factors. From a policy standpoint, it appears that the medical community can have a major impact by finding ways to assess and address the needs of individual family members. Promoting the health and functioning of each family mem-

### What This Study Adds

Previous studies indicate that children with disabilities are at an increased risk for psychological morbidity. However, nearly all of these studies have been conducted on convenience samples, suggesting a need for population-based studies to confirm these findings. Drawing from a national sample of children with disabilities and their mothers, this study demonstrated that learning impairments and reported family burdens were the strongest correlates of maladjustment in school-aged children with disabilities.

ber reduces the stressors on the family as a whole, which can potentially create a salutary family environment.

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